Pontifícia Universidade Católica
do Rio de Janeiro

Bruno Azevedo Chagas

End-User Configuration in Assistive Technologies:

A case study with a severely physically impaired user

Dissertação de Mestrado

Dissertation presented to the Programa de Pós-Graduação em Informática of the Departamento de Informática, PUC-Rio as partial fulfillment of the requirements for the degree of Mestre em Informática.

Advisor: Prof. Hugo Fuks
Co-Advisor: Prof. Clarisse Sieckenius de Souza

Rio de Janeiro

September 2015

Pontifícia Universidade Católica
do Rio de Janeiro

Bruno Azevedo Chagas

End-User Configuration in Assistive Technologies:

A case study with a severely physically impaired user

Dissertation presented to the Programa de Pós-Graduação em Informática of the Departamento de Informática do Centro Técnico Científico da PUC-Rio, as partial fulfillment of the requirements for the degree of Mestre.

Prof. Hugo Fuks
Advisor
Departamento de Informática - PUC-Rio

Prof. Clarisse Sieckenius de Souza
Co-Advisor
Departamento de Informática - PUC-Rio

Prof. Alberto Barbosa Raposo
Departamento de Informática - PUC-Rio

Prof. Simone Diniz Junqueira Barbosa
Departamento de Informática - PUC-Rio

Prof. Jose Eugenio Leal
Coordinator of the Centro Técnico Científico - PUC-Rio

Rio de Janeiro, September 4th 2015

Bruno Azevedo Chagas

Bruno holds a degree in Computer Engineering from Universidade Estadual de Campinas (UNICAMP, 2000) and has extensive experience in the areas of software engineering, architecture, development and integration. Currently, he works as software developer and is an entrepreneur in the tech industry.

Bibliographic data

Chagas, Bruno Azevedo

End-User configuration in assistive technologies : a case study with a severely physically impaired user / Bruno Azevedo Chagas ; advisor: Hugo Fuks ; co-advisor: Clarisse Sieckenius de Souza. – 2015.

124 f. : il. (color.) ; 30 cm

Dissertação (mestrado) – Pontifícia Universidade Católica do Rio de Janeiro, Departamento de Informática.

Inclui bibliografia.

1. Informática – Teses. 2. Tecnologia Assistiva. 3. Configuração. 4. End-User Development. 5. Computação ubíqua. I. Fuks, Hugo. II. De Souza, Clarisse Sieckenius. III. Pontifícia Universidade Católica do Rio de Janeiro. Departamento de Informática. IV. Título.

CDD: 004

To those who may benefit from this work.

Acknowledgements

First and foremost I thank God, for the countless opportunities of new beginnings.

I thank my parents for the comprehensive support, quiet and always present, free and unlimited from “day one”. And my brother, for his friendship throughout my life, and for the early morning rides, throughout this course.

I would like to thank my advisors Prof. Hugo Fuks and Prof. Clarisse Sieckenius de Souza, for their directions, comments, suggestions, continuous support and immense knowledge and time sharing. I also thank them for the partial funding with equipment and travel in this research.

I express my sincere gratitude to the research participants without whom this work would not have been possible and whose names are preserved in respect to their privacy and to the research protocol: thank you for your valuable time, for your cooperation and for teaching me much more than I can write here.

I thank the colleagues from Second Lab and the Semiotic Engineering Research Group (SERG), for their friendship, patience, insights and discussions over the course of this research: Bruno, Cleyton, Débora, Fernando, Ingrid, Juliana, João, Katia, Luciana, Luiz, Marcelle, Priscilla and Wallace. Special thanks to Carla Leitão for her methodological experience sharing, Rafael Brandão, for his help in critical moments, and Marcio Cunha, for opening the way and opportunities.

I would also like to thank all the professors, friends and colleagues from PUC-Rio post-graduate program whose names would be too many to mention here, with whom I shared classes, study hours or just coffees, enough to make me admire them all. Special thanks to Alain Dominguez Fuentes and Alejandro Diaz Centeno for the cooperation in developing the first prototype version.

Finally, I thank PUC-Rio and CAPES for the partial financial support.

Abstract

Chagas, Bruno Azevedo; Fuks, Hugo (Advisor); de Souza, Clarisse Sieckenius (Co-Advisor). **End-User Configuration in Assistive Technologies: A case study with a severely physically impaired user**. Rio de Janeiro, 2015. 124p. MSc. Dissertation – Departamento de Informática, Pontifícia Universidade Católica do Rio de Janeiro.

Assistive Technology (AT) aims at compensating for motor, sensory or cognitive functional limitations of its users. One of the reasons AT is hard to design and turn into a product is the variability of kinds and degrees of disabilities and individual characteristics among users (physical, psychological, cultural and environmental). This variability can be addressed by means of configurations. This work takes as a starting point the premise that the ability for the end-user to adapt AT may have the potential to improve user's experience and the quality of the products. However, before engaging in such endeavor we must answer questions like: what is configuration in the AT domain? What does AT mean to users (and stakeholders)? What could, should or should not be configured and how? In this work, we conducted a case study mixing ethnography and action-research with a single tetraplegic participant who came to our lab seeking for technology that could help him in his daily life. First, we interviewed him and observed his daily needs and activities and then we developed an AT platform prototype that controls some devices to be operated simultaneously by gesture and voice interaction in "his smart home." Throughout two action-research cycles, we investigated interaction and technological issues regarding our prototype configuration and use. Based on our findings, we propose a set of dimensions and a collaborative framework for AT configuration. Our main contribution is to propose a conceptual structure for organizing the AT configuration problem space to support the design of similar technologies.

Keywords

Assistive Technology; Configuration; End-User Development; Ubiquitous Computing.

Resumo

Chagas, Bruno Azevedo Fuks, Hugo (Orientador); de Souza, Clarisse Sieckenius (Co-Orientadora). **Configuração pelo Usuário Final em Tecnologias Assistivas: Um estudo de caso com um usuário com limitação física severa**. Rio de Janeiro, 2015. 124p. Dissertação de Mestrado – Departamento de Informática, Pontifícia Universidade Católica do Rio de Janeiro.

Tecnologia Assistiva (TA) visa compensar limitações funcionais motoras, sensoriais ou cognitivas de seus usuários. Uma das razões pela qual TA é difícil de projetar e transformar em um produto é a variabilidade dos tipos e graus de deficiência e das características individuais dos seus os usuários (físicas, psicológicas, culturais e ambientais). Esta variabilidade pode ser tratada por meio de configurações. Este trabalho tem como ponto de partida a premissa de que a capacidade para o usuário final de adaptar a TA pode ter o potencial para melhorar a experiência de uso e a qualidade dos produtos. No entanto, antes de empreender tal esforço, devemos responder a perguntas como: o que é configuração no domínio da TA? O que significa a TA para os seus usuários (e para as pessoas ao redor deles)? O que pode, deve ou não deve ser configurado e como? Neste trabalho, foi realizado um estudo de caso que mistura etnografia e pesquisa-ação com um único participante tetraplégico que veio ao nosso laboratório em busca de tecnologia para ajudá-lo em sua vida cotidiana. Primeiro, nós o entrevistamos e observamos suas necessidades e atividades diárias e, em seguida, desenvolvemos uma plataforma protótipo de TA que controla alguns dispositivos, operada simultaneamente por gesto e interação de voz em "sua casa inteligente." Ao longo de dois ciclos de pesquisa-ação, investigamos questões de interação e tecnológicas em relação à configuração e ao uso do nosso protótipo. Com base em nossos resultados, propomos um conjunto de dimensões e um framework colaborativo para a configuração de TA. Nossa principal contribuição é propor uma estrutura conceitual para organizar o espaço do problema de configuração de TA que pode apoiar a criação de tecnologias semelhantes.

Palavras-chave

Tecnologia Assistiva; Configuração; End-User Development; Computação Ubíqua.

Contents

List of figures

List of tables

1
Introduction

Assistive Technology (AT) aims at compensating for motor, sensory or cognitive functional limitations of its users. In Brazil, the most accepted definition states that:

> "Assistive Technology is an interdisciplinary area of knowledge, encompassing products, resources, methodologies, strategies, practices and services that have the objective to promote the functionality, related to the activity and participation of people with disabilities, impairments or reduced mobility, aiming their autonomy, independence, quality of life and social inclusion." (BRASIL, Subsecretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência, Comitê de Ajudas Técnicas, 2009, our translation)

As technology has come to play an increasingly important role in the lives of the 21st Century citizens, as one of the primary engines for economic activity, education, and innovation throughout the world, it is clear that that access to mainstream technology has profound implications for individuals with disabilities, and AT is fundamental in providing it. Because of that, most AT definitions focuses on the disabled person, emphasizing the role of AT as equipment for social inclusion, which is the case in Brazil (BRASIL, Presidência da República, 1999). However, there are insufficient incentives for commercial pursuit of the application of technology devices to meet the needs of individuals with disabilities, because of the perception that such individuals constitute a limited market, justifying governments' interventions as a way to foster the availability of assistive products and services by means of public policies, such as (United States (105th Congress), 1998) and (BRASIL, Presidência da República, 2011). This work takes a different perspective on the problem, exploring some of the challenges in AT product development in order to help to solve them. Ultimately, we believe it can foster AT availability and adoption independently of government stimuli because we also believe that the design of technology should look beyond external functionality and esthetics, including the "inner design" that influences both and, moreover, the development, availability, efficiency and sustainability of any product.

One of the many reasons AT is hard to design and turn into products is the variability of kinds and degrees of disabilities and individual characteristics among users (physical, psychological, cultural and environmental). This variability can be addressed by means of configurations. This work takes as a starting point the premise that the ability for the end-user to adapt AT has the potential to improve user's experience and the quality of the products. However, before engaging in such endeavor we must answer questions like: what is configuration in the AT domain? What does AT mean to users? And who are the users (and stakeholders) of such systems? What could, should or should not be configured and how?

In this work, we conducted a case study mixing ethnography and action-research with a single tetraplegic participant who came to our lab seeking for technology that could help him in his daily life. First, we interviewed him and observed his daily needs and activities and then we prototyped an AT platform that controls some devices by gesture and voice interaction in "his smart home." Throughout two action-research cycles, we investigated interaction and technological issues regarding our prototype configuration and use. Early in this process, we realized that we were dealing not with a single user, but with a group of people, leading us to extend this notion of end-user from one single person to a small group of people, including not only the main user (the disabled) but also the persons around him, such as family members and caregivers in our case, often referred here as stakeholders. Based on our findings, we propose a set of dimensions and a collaborative framework for AT configuration. Our main contribution is a conceptual structure for organizing the AT configuration problem space. We believe that it could also support the design of similar technologies.

This dissertation is structured as follows: This section introduces the outline of our main goals, motivations, contributions and the methodology for this research. Section 2 presents an overview about the main topics of our research, some scientific and technological background, as well as the motivations in investigating them together. Section 3 provides a literature review to give the reader an overview of the state-of-the-art of the domain that we tackled. Section 4 describes our research approach and the motivations behind it, as well as the circumstances and participants who motivated and guided our work. Section 5 reports the two research cycles we went through, following a typical action research cycle template. In Section 6, we propose a conceptual structure for organizing the AT configuration problem space. Finally, Section 7 presents our finals considerations, highlighting our main contributions mentioning other topics that influenced and can be influenced by our work and pointing to future work.

2
Context

In this section we give a general overview about the main topics of our research, as well as the main motivations in investigating them. Despite the challenges and broadness of the scope, we explain the main reasons why we think that approaching them together may bring significant benefits, offering different perspectives from what is usually seen when each topic is researched isolated. This is not a literature review, but prepares the terrain for it, which will be presented on the following section (Section 3).

2.1.
End-User Development

One approach to designing usable and enjoyable computer applications is to say that designers need better methods and tools to understand users and their contexts, and to encode this understanding into closed computer systems. Another is to acknowledge that there will always be unattended user needs, and that the way to increase users' satisfaction is to help them modify systems in order to meet constantly changing requirements (de Souza & Barbosa, 2006). End-User Development (EUD) can be defined as "a set of methods, techniques, and tools that allow users of software systems, who are acting as non-professional software developers, at some point to create, modify or extend a software artefact" (Lieberman, et al., 2006). In a world where technology evolves rapidly becoming more pervasive by the day, where places, objects and things around us start to be endowed by software defined behavior, this becomes increasingly important in its individual, social and economic implications, because it directly addresses the ability of people to act and control the world around them.

2.2. Internet of Things

The Internet of Things (IoT) concept was coined in 1999 by Kevin Ashton and his team at MIT's Auto-ID Center with the initial focus on developing universal electronic identification codes of products to support the widespread use of RFID (Radio-Frequency IDentification) in commercial networks (Ashton, 2009). But it rapidly spread around encompassing a much broader concept thanks to the evolution of sensor, embedded electronics and mobile (wireless) communication technology. The basic idea is the widespread presence of a variety of things – identified objects, sensors, actuators, computers, cell phones, etc. – that, through wireless communication and unique ID, are able to interact with each other and collaborate with its neighbors to achieve common goals (Atzori, et al., 2010). Today, multiple definitions and facets of the Internet of Things are described by the scientific community. This attests to the strong interest in the subject, encompassing a wide variety of technologies, domains and applications, as well as ethical and social issues such as security and privacy, which form extensive field of research topics, many still under investigation (Atzori, et al., 2010).

The connection of physical things with the Internet makes it possible to access remote sensor data and control the physical world at distance, where *smart objects* form the building blocks of a new reality of ubiquitous computing (Kopetz, 2011). Because of the potential for technology innovation in many of the current business practices, the Internet of Things also attracts the industry interest, especially (but not only) of the technology and telecommunications sectors:

> "The next step in this technological revolution is to connect inanimate objects and things to communication networks. This is the vision of a truly ubiquitous network – 'anytime, anywhere, by anyone and anything'." (ITU - International Telecommunication Union, 2005).

There is real potential for significant social change, which is why the topic has attracted the attention of researchers, enterprises and governments worldwide. The potential ranges from infrastructure, home, commercial and industrial automation, new products, services and interactive environments, entertainment and digital art, to innovations in public services and healthcare applications. In the latter sense, there is a very large room for a new class of technologies and applications that can considerably benefit the life of people with special needs due to functional limitations.

2.3. Assistive Technology

According to the World Health Organization (2014), over a billion people, about 15% of the world's population, have some form of disability. Between 110 million and 190 million adults have significant difficulties in functioning. Rates of disability are increasing due to population ageing and increases in chronic health conditions, among other causes. Moreover, people with disabilities report seeking more health care than people without disabilities and have greater unmet needs (World Health Organization, 2014). They are the largest minority in the world, and about 80% of these people live in developing countries. According to the United Nations, among the poorest people in the world, 20% have some form of disability (United Nations in Brazil, s.d.). The latest census in our country (2010) indicates that almost 24% of the population has some kind of disability, which is approximately 45.6 million of Brazilians. Among them, we can find a great variability of types (visual, auditory, motor or intellectual/mental, also known as cognitive), levels of limitations (a continuum between *"some difficulty"* and *"cannot in any way"*), causes (genetics, accidents, aging) and personal characteristics (physical, such as height and weight, their social, psychological, etc.). About 8.3% have a severe disability, whether visual, auditory, motor or intellectual/mental, representing approximately 15.7 million people (Oliveira, 2012); (IBGE - Instituto Brasileiro de Geografia e Estatística, 2010). Gradually, the society has changed the focus from beyond the medical aspect (healthcare and treatment) and started to consider it as a matter of social inclusion, which involves the guarantee of human rights and of the full and active participation of individuals with disabilities in society.

Moreover, it is a theme whose scope goes far beyond the numbers presented here: functional limitations of various kinds affect everyone in different degrees and moments of their lives. Either by aging or even under everyday circumstances, we are all subject to experiencing functional limitations when: we have compromised mobility due to an injured leg (motor), we have the movements of the upper limbs compromised because our hands and arms are busy holding a baby or several shopping bags (motor), the street noise in a busy location harms our hearing (auditory), intense stress situations limit our ability to assess the reality around us (mental / intellectual). That said, disability can be viewed under the following perspective:

> "Disability is the inability to accommodate to the world as it is currently designed." (Vanderheiden, 2012)

This definition draws attention to the relationship between disability and design, as well as to the possibility of both being modified, about what there are three possible approaches:

- Change the person through medical treatment, surgery, implants and/or even education and special training;
- Equip people and/or the objects and places with tools that allow users with special needs to access and use they in the form they are currently designed;
- Change the current state of the world, through the design of more accessible and universal places, products and services.

In this work, we took the second approach, using the term Assistive Technology (AT) to denote the set of specialized tools that can adapt parts of the world around us (products, objects, services or places) to the specific skills and abilities of individuals with functional limitations so that they can use them. In Brazil, the terms "Assistive Technology", "Technical Assistance" and "Supportive Technology" are commonly used interchangeably (Galvão Filho, 2009), and are defined as "Technical Assistance" by the following law:

> "The resources that allow for compensating one or more motor, sensory or mental limitations of the disabled person, in order to overcome the barriers of communication and mobility and to enable their full social inclusion." (BRASIL, Presidência da República, 1999, our translation)

2.4. This work

In our research, we linked the topics of End-User Development (EUD) and Internet of Things (IoT) to develop scientific and technological advances in the field of Assistive Technology (AT). Indeed, related technologies already available today enable the access to existing devices, objects and services through new interaction and communication mechanisms that offers a potential already envisioned by researchers in the accessibility field:

> "As we move toward having environments where the products can all be controlled remotely (because it is convenient for everyone), and as we move to the situation where everyone pulls out a natural language enabled cell phone or PDA to have the devices in their environment operated, we begin to have a situation where individuals with disabilities are able to use the same devices, using these same "user friendly" interfaces, as everyone else." (Vanderheiden, 2007)

However, although it seems technologically feasible, the situation envisioned by Vanderheiden does not seem to be the prevailing one yet. On a subsequent paper, the same author says that assistive technologies lag behind mainstream technologies in both compatibility and functionality; that effective assistive technologies are often beyond the financial reach of those who need them; that effective assistive technologies are not available in many countries and many languages (Vanderheiden, 2008). Indeed, we have confirmed this to be our case in Brazil, at least within the subset we have studied. Our research aims to show that IoT technologies can be used as infrastructure for AT to the benefit of the people who need it, due to its high versatility, larger availability and consequent lower costs.

One of the reasons AT are hard to design, produce and be used is the variability of kinds and degrees of disabilities and unique individual characteristics among users (physical, psychological, cultural, and environmental, etc.). Trying to address the specific characteristics of each disability and its carriers and how they influence and are influenced by a proposed AT is challenging to researchers, product designers and producers and, at the end, to the users themselves, who may have trouble when using the technology. Possibly, this variability can be addressed by means of configurations to improve production and adoption if an AT system or device offers enough flexibility to be adapted to the specific characteristics and needs of its users. But usually, these specific characteristics and needs are only discovered in real use case situations, when users try to use the technology in their real context of life. That is why we seek to investigate an approach that would allow the configurations to be done by the end-users such as the one proposed by EUD. Sometimes, this is called design for user empowerment and it has already been envisioned by Ladner (2008) in the AT domain:

> "A key concept that has emerged in the past ten to fifteen years is that of user centered design, where computer interface design is optimized around what the users can and want to do rather than forcing users adapt themselves to the interface. For persons with disabilities this means involving them in the design process from beginning to end. Augmenting this concept is one that I believe is equally important for this group, namely, design for user empowerment. This means designing tools that help empower persons with disabilities to create and/or configure accessibility products on their own. Since they are the most motivated to improve their lives using technology, if the mechanisms exist to empower them to do it on their own, they will."

3
Related work

Our work is currently investigating interaction and technology in the intersection of three extensive research areas, depicted in Figure 1. This section is not an exhaustive review of the research done in each of the three areas (this is beyond the goal of this research, given that it would be probably unfeasible to us due to the necessary time and effort for accomplishing it). Instead, we want to highlight the research we think can show important approaches and advances, especially in the intersection between them, in order to give the reader a comprehensive overview of the state-of-the-art in the domain we chose.

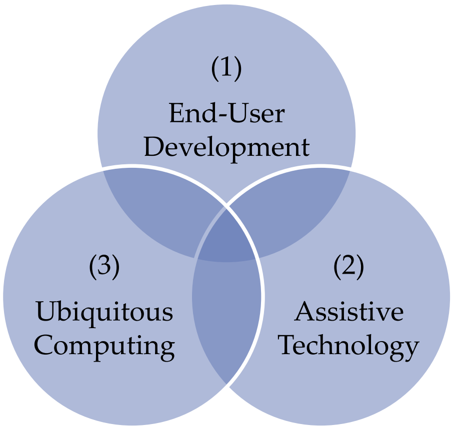

Figure 1 – A depiction of the research areas of our work.

3.1.
End-User Development and Assistive Technology

The intersection between End-User Development (EUD) and Assistive Technology (AT) was investigated by Carmien & Fischer (2008) applying the meta-design framework in systems for helping people with cognitive disabilities. Meta-design is a conceptual framework aimed at defining and creating social and technical infrastructures in which new forms of collaborative design can take place (Fischer & Giaccardi, 2006). It extends the traditional notion of system development to include users in an ongoing process as co-designers, not only at design time but throughout the entire existence of the system (Fischer, et al., 2004). It is grounded in the basic assumption that future uses and problems cannot be completely anticipated at design time, when a system is being developed. Users, at use time, may discover mismatches between their needs and the support that an existing system can provide for them. The basic idea is that given that users learn to operate a system and adapt to its functionality, the system should be modifiable in order to adapt to the situated practices and needs of its users.

Carmien & Fischer proposed, designed and evaluated a system called "Memory Aiding Prompting System" (MAPS) to support people with cognitive disabilities to accomplish activities of daily living (ADLs), such as cooking, housework, or shopping, which can be difficult for them because of their memory or reasoning limitations. They say a unique challenge in this domain is that the end-users themselves cannot act as designers because of their disability; the caregivers must perform the role of "end-user developers". MAPS was end-user programmable and was divided into two parts: one for the caregivers, in which they create multimedia scripts to support their patients with particular tasks; another to be used by their patients, which presented them the pre-programmed multimedia scripts with a step-by-step guide to accomplish some task.

Also in the domain of cognitive disabilities, Lewis (2007) has pointed at configurability needs and some other aspects of design that can enhance the simplicity of an AT system interface. He discusses configurable interfaces as an intermediate point on a spectrum of possible interface designs that can go from fully static – that is, an immutable interface – to fully dynamic – that is, an interface that automatically adapts to variable user's needs. A configurable design can respond to differences among users in what they need to do (or even to changes in what a single given user needs to do over time), at the cost of increasing the complexity of the system because of the configuration apparatus. The user will have to deal with it while using the application in several aspects of the system, e.g. in the interface itself, in the manual, help screens, etc. An interesting arrangement he suggests to deal with it is to "share the load" of configuration, making it accessible by third parties, as a way to provide an attractive division of labor. In this way, someone else configures the application appropriately for the user, who may focus on using the system with the benefit of a stable and finely adjusted interface (and possibly with less configuration-related clutter).

A different approach in a different domain has been researched by Bigham & Ladner (2007) who propose a collaborative scripting framework that web users, web developers and web researchers can use to improve collaboratively web accessibility for blind users. They called it "Accessmonkey" because it was derived from Greasemonkey[1], a popular EUD extension for the Firefox web browser. Usually, blind web users access the web using screen readers, but these present a web experience destituted of the rich visual structure of modern web sites (because of problems in the web sites' HTML codes and/or dynamic web content.) Using Accessmonkey, web users and developers on different platforms can collaboratively adapt web content according to user needs, which usually depends on the screen readers' specific features and are not available to the developers when coding and testing web pages. Later, Bigham, et al. (2010) proposed a technology they called "Accessibility by demonstration" that enables end-users to guide developers to correct web accessibility problems by retroactively recording the real accessibility problems they face at the time they experience them. In this approach, the users are in charge for defining and re-questing the changes that they need (actually, corrections in this case) in their context and during use time, even though they will not be the ones who will code the system changes.

The works above suggest a common requirement in the AT domain: usually, some collaboration will take place around the technology being proposed or used to the benefit of a main user – the disabled one. However, how does this collaborative process takes place and how to support it is usually considered apart from the AT itself, or not considered at all.

3.2. End-User Development and Ubiquitous Computing

The intersection between End-User Development (EUD) and Ubiquitous Computing (Ubicomp) seems to be a topic of much interest these days. First, we must say that, so far, we have referred to the Internet of Things and how it can

[1] Greasemonkey Firefox extension: http://www.greasespot.net/ [Accessed on 7th July 2015].

provide technological infrastructure to a new breed of products, services and environments based on a widespread network of sensors, wireless communication technology and embedded computation into everyday objects and places. Ubiquitous Computing (Weiser, 1991) is not the same thing of Internet of Things: the former precedes the latter, coined only in 1999 (Ashton, 2009). However, the two concepts are strongly related nowadays and merge in many aspects. Ubiquitous Computing proposes to enhance computer use by making many computers available throughout the physical environment, while making them effectively invisible to the user, who would be continually interacting with hundreds of nearby wirelessly interconnected computers (Weiser, 1993). The Internet of Things seems to be the current concrete technological infrastructure that is giving life to this vision, merging low cost sensors, actuators and microcontrollers with the power of the Internet and the World Wide Web as we know today. As a research field, we choose to refer to it from the perspective of the Ubiquitous Computing concept because it covers our topics of interest and is more independent of current technological implementation and trends. However, it will not make much difference to our main concerns here, and will often refer to them interchangeably, without damage to the main ideas.

Ur, et al. (2014) did a research with a popular tool (IFFT - https://ifttt.com) which is currently being used to help users handle Ubicomp scenarios in smart homes, a typical expected use case. They call it “trigger-action programming”, which is a programming environment that empowers the user to combine high level events – triggers, usually detected by sensors, in this context – with actions, using an automated “IF-THIS-DO-THAT” rule engine (for example: “send me a message if some door opens when I am not in the house”, and the like). They say the need for such EUD engine in this and other similar scenarios may be due to a combination of factors, such as the great diversity – and consequent unpredictability – of behaviors users will want, and also because of the great amount and diversity of *apps* users will need to accomplish the desired goals, some of which they will not be able to find in common market places, such as *app stores*. Similar automated rule-based engines exist like Atooma (http://www.atooma.com/) and some with a slight variation allow for rules of the kind “WHEN-TRIGGER-THEN-ACTION”, like Wewiredweb (https://wewiredweb.com/). Barricelli & Valtolina (2015) say EUD represents the ideal approach for empowering the end-users and make them becoming unwitting developers in their own IoT environment. They have researched the current state-of-the-art in EUD for IoT and point to the above mentioned tools and other similar ones. They conclude by proposing a new EUD language that extends the IF-THIS-DO-THAT / WHEN-TRIGGER-THEN-ACTION rules with more expressive power to allow for the definition of time and space related conditions. Other recent works are dealing with this topic, proposing others kinds of EUD tools, languages and frameworks with similar purposes, some focusing on how to uniformly program different devices and platforms (Kubitza & Schmidt, 2015), some proposing the use of Complex-Event-Processing technology as a more powerful end-user programming environment (Dax, et al., 2015), and some researching the theoretical aspects that influence the design of such tools and languages (Perera, et al., 2015).

The programming of this kind of technology may seem to be a contemporary topic (or even “futuristic” to some audiences), but there is some tradition of research about it. Newman, et al. (2002) described a possible future they were visualizing in which arbitrary devices and services would be interconnected and used without prior knowledge of one another. They believed that users would wish to create configurations and combinations to create particular scenarios that no application developer had foreseen. Later, Davidoff, et al. (2006) said the end-user programming approach would have several benefits for a smart home system because it provides users control over an unpredictable confederation of interoperating devices and allows users to customize services as they might see fit, even inventing new services. They conducted an ethnographic study with American families and, based on it, they suggested that researchers should study the topic not only in terms of the control of devices, artifacts and tasks, but also considering the control of the things families value the most, namely: their time, their activities, and their relationships. Finally, they argue that the way to do this is to enable end-user programming systems to more flexibly and appropriately reflect the complex nature of observed human interaction in such context. They propose seven design principles that they believe smart home researchers should address in the systems they build, in order to achieve it, most of which, in our opinion, indicate the strong need for flexibility in such kind of technology, such as: allow for the organic evolution of routines and plans; easily construct new plans and routines, and modify existing ones; understand periodic changes, exceptions and improvisation; design for breakdowns; and account for multiple, overlapping and occasionally conflicting goals.

Another interesting set of studies about pervasive networking of domestic appliances were made in the context of the Cambridge AutoHAN project (Blackwell & Hague, 2001-a). Keeping in mind the technology changes that were occurring by that time, they anticipated the situation of Ubicomp with IoT in many aspects, because the home environment was already (by that time and even more these days) particularly rich in terms of computation, with a typical home having dozens of devices, like microwave ovens, TVs and VCRs. They also proposed an end-user programming approach for such a context to integrate these devices and to add utility to the networked infrastructure (Hague, et al., 2001). Differently from the previous approaches, they proposed the use of tangible physical objects as language components, creating a programming language they called “Media Cubes”: a set of cubes with embedded electronics to communicate with each other and with some home appliances that allow for the user to program by placing them aside (Blackwell & Hague, 2001-b); (Blackwell, 2004). It is another style of interaction that makes use of Tangible User Interfaces (TUIs) (Ishii & Ullmer, 1997), contrasting to the more traditional screen, keyboard and mouse based Graphical User Interfaces (GUIs) of desktop computers. Dourish (2004) says tangible computing “expands the ubiquitous computing vision by concentrating on the physical environment as primary site of interaction with computation” (Dourish, 2004). This style of computation emphasizes (to varying degrees) a number of concepts: tangibility and materiality of the interface, physical embodiment of data, and the embedding of the interface in real spaces (Elumeze, 2010). “Tangible programming” refers to the composing and executing of programs in physical spaces, as opposed to writing them entirely within a computer (Elumeze, 2010). Programming in this style has been researched mostly for educational purposes, with a particular focus on teaching children and novice programmers computation through technology construction kits and toys (Schweikardt & Gross, 2007) and other alternative means and languages for programming (Eisenberg, et al., 2009). Elumeze (2010) pushes this concept further and proposes a different approach he called “Ambient Programming”, which, in his words, “reconceives programming as an opportunistic, physically active, and playful activity, situated within the very same physical context as the pervasive systems being built". In this approach, he suggests that artifacts should be designed not as stand-alone, closed systems, but rather with an eye toward their interaction with a wide range of other devices, so to build an "ecosystem" of devices and tools – a wide collection of artifacts with at least some degree of mutual compatibility that can be "mixed-and-matched" in different forms.

Up to now, the main EUD approaches have focused on the desktop platform: for example, desktop spreadsheets have been the most used EUD tools so far (Lucci & Paternò, 2014). But we can notice a trend in EUD research, from the *desktop* (Nardi, 1993); (Cypher, 1993), to mobile *phones* (Cuccurullo, et al., 2011); (Maues & Barbosa, 2013); (Lucci & Paternò, 2014), to smart *devices and ecosystems* (already mentioned above), naturally following a global trend in technology development and adoption. In this last trend, this topic is also being influenced by the popularization of open hardware platforms, where the Arduino (http://www.arduino.cc/) undoubtedly represents the most popular example. In this scenario, the end-user may customize not only software, but build, extend or *hack* hardware, what expands the possibilities of tailoring a technology. Given that the building of hardware and software often happens together in these scenarios, there are studies of end-user programming of hardware platforms, such as (Millner & Baafi, 2011) and (Booth & Stumpf, 2013). Together with the advent of other digital fabrication technologies, such us 3D printers, this is contributing to the dissemination and growth of the "Do-It-Yourself" (DIY) culture, now with a technological and innovative bias, forming the so called "Maker Movement" (Hatch, 2013); (Anderson, 2014). There are interesting discussions about this topic and its current and possible implications in (Mota, 2011) and (Lindtner, et al., 2014) from the innovation and economic perspectives. However, we need to better understand the phenomenon and its possibilities in order to support it with a reasonable theory and with a comprehensive set of integrated tools from the technological perspective.

3.3.
Assistive Technology and Ubiquitous Computing

There is also a recent volume of research about Ubiquitous Computing (Ubicomp) and Assistive Technology (AT), or, more generally, in healthcare applications. The focus of this research goes from wireless sensor networks for healthcare (Alemdar & Ersoy, 2010); to smart homes instrumenting healthcare applications, including AT (Chan, et al., 2008); (Chan, et al., 2009); (Stefanov, et al., 2004); to the use of wearable computers for health monitoring (Chan, et al., 2012) and specifically as AT devices (Ross, 2001). The last four references include the analysis of such technologies as AT and mention several cases and projects where that was the case. Usually, smart homes are considered to be an effective way for providing remote healthcare services, especially to the elderly and disabled who do not require intensive healthcare support (Alam, et al., 2012). But Chan, et al. (2009) point the lack of studies related to user needs as a major barrier to the implementation of health care technology in smart homes. In a subsequent work they also identify the lack of research in what they call deployment issues, such as service organization, privacy, user needs, acceptance, system security and safety, and economic and financial issues. They consider it to be “the paramount research focus over the next few decades” (Chan, et al., 2012). Regarding our topic here, they also say that one of the challenges is that people have different needs and provision by a decentralized healthcare system (such as one partially based on smart homes) has to be tailored to individuals. Therefore, how to build this tailorable systems seems to be of paramount importance also from this perspective.

An example of AT in the smart-home domain is given by Mihailidis, et al. (2008), who designed and evaluated an intelligent system that leverages machine learning and computer vision to prompt Old Adults With Dementia (OAWDs) through activities of daily living (ADLs). The system has a similar purpose as in (Carmien & Fischer, 2008), but with a different technology and approach, based on artificial intelligence. Actually, this is the usual approach for “smart-*” technology, and currently one of the reasons (if not the main reason) why they are called “smart”, meaning that they are able to perceive, infer and act automatically by itself (without human intervention) at some level. On a subsequent research from the same group, Hwang, et al. (2012) highlights the importance of considering others stakeholders' needs in this context – namely, the informal caregivers of OAWDs – to inform the design for the smart home User Interfaces. Finally, Hwang & Hoey (2012) discuss the gap that exists between the caregivers of older adults attempting to age-in-place and sophisticated smart-home systems that can sense the environment and provide assistance when needed. They argue that smart-home systems need to be customizable by end-users and that although they can provide mechanisms for engineers and designers to build and adapt smart-home systems, these mechanisms are not easily understood by or sufficiently user-friendly for actual end-users such as older adults and their caregivers. They propose an approach they call the "D.I.Y. Smart Home" which "connects users with developers by building a person-specific logical knowledge base of user needs, assistance dynamics, sensors, actuators and care solutions". Despite the use of the term "D.I.Y.", their approach is strongly based on artificial intelligence (machine learning) and although they say the system would dynamically evolve and be customizable in real-time by end-users and product developers, it is not said how it would be done (*e.g.*, how the user would intervene in the inputs, outputs, parameters or even the in the algorithms their selves, for example).

Another interesting example which is closer to the domain that we are tackling – motor disabilities – is given by (Nguyen, et al., 2008), who prototyped an assistive robot called "El-e" designed to help people with severe motor impairments manipulate everyday objects. El-e can autonomously approach an indicated 3D location and pick up a nearby object. The same research group have developed and tested three distinct interfaces that can enable a severally impaired user to provide a 3D location to El-e: an ear-mounted laser pointer, a hand-held laser pointer, and a touch screen interface (Choi, et al., 2008). They focused on usability evaluation of the devices with users with amyotrophic lateral sclerosis (ALS) and concluded suggesting that different individuals would benefit from different user interfaces to assistive robots and that a "one-size-fits-all solution" would not work. To us, this is a strong indicator of configuration needs, that is corroborated by others researches: also in the motor impairments domain, Kane et al. (2009) make recommendations for increasing configurability in the design of mobile accessible devices for users with motor impairments; Carrington, et al.

(2014) explores different design configurations – wearables and “chairables” – for improved mobile devices accessibility to wheelchair users; and quite recently Malu & Findlater (2015) say that a personalized wearable approach offers a promising direction for providing mobile computing access to users with upper body motor impairments. However, what this configurability is and how it can be achieved is far from clear.

It has also been done some advanced work in the rehabilitation field about exoskeletons (Dollar & Herr, 2008) and combining it with brain-machine interfaces (Lebedev, et al., 2011). We acknowledge their potential, but at the current technological stage, most of this research focus on engineering or clinical aspects, have expensive costs and need medical support, what put it out of our possibilities.

Still on this territory, we can find also some research concerning “Do-It-Yourself Assistive Technology”, or simply “DIY-AT” (Hurst & Tobias, 2011); (Hurst & Kane, 2013). From previous research on adoption of AT in the USA, they noted that a large percentage of AT devices that are purchased end up unused or abandoned due to several psychological, social and technical factors. They found that increased control over design elements, passion, and cost motivated individuals to make their own Assistive Technology instead of buying it. Their aim is to help more people gain access to the assistive technology they need by empowering non-engineers to "Do-It-Yourself", and thus create, modify, or build their own assistive technology. They discuss how a new generation of rapid prototyping tools and online communities can empower more individuals, and propose developing more accessible software tools for designing and customizing physical object prototypes. However, they do not approach the building of software (in fact, not even the electronic hardware) that could be embedded in the physical objects and this the reason why we think their research fits in this sub-section and not in the previous one, neither in the intersection of all three areas.

3.4.Additional remarks

As was said in the beginning of this session, our work is investigating the intersection of three extensive research areas, namely: End-User Development, Assistive Technology and Ubiquitous Computing. Despite the great volume of research in each of them individually, there is not much research even in the intersections two-for-two. To the best of our knowledge, there is no significant volume of research focusing on the intersection of the three areas. We have found (Moraiti, et al., 2015) to be among the closer scarce examples. They propose and evaluate a DIY-AT toolkit that "can be positioned at the intersection of tangible interaction, assistive technology and the DIY approach," they say. The toolkit was designed to be used by Occupational Therapists (OTs) in developing therapeutic activities that could remediate impairments and functional limitations of their patients. It includes some squeeze sensors, a microcontroller board and some other electronics together with a new standalone software program they created to allow the configuration and mapping of gestures to game commands by the end-user programmatically. They say their approach is able to deliver a diversity of solutions tailoring a diversity of clients and supporting the therapists' creativity. Similarly, others researchers are investigating how to incorporate digital fabrication and electronic prototyping techniques into the practices of OTs and AT practitioners (Lin, et al., 2014). Despite the promising approach, more research is needed to elucidate how it can be effectively done.

The topic seems socially and technologically important enough to deserve more investigation. Its intrinsic complexity and challenges make it unrealistic to think that it can be well understood with so few research. Besides the obvious impact on the lives of people with disabilities, it is already known that this type of research, involving technology and disability, promotes scientific and technological development, especially in the Computer Science filed, usually leading to innovations that are beneficial to all users, including those who are not disabled (Glinert & York, 2008). We want to contribute in this direction and we took the works briefly described above to support our research path.

From this starting point, we identify some aspects that are frequently mentioned and served as directions to be followed. We summarize those we think are of utmost importance to our research here as follows. Firstly, we note that collaboration is a common requirement in the AT domain, as we could notice mainly in the first sub-section (EUD-AT intersection – Section 3.1). However, the collaborative process that happens around it is usually not investigated. Secondly, it seems a consensus from the second sub-section (intersection EUD-Ubicomp – Section 3.2) that EUD is a powerful tool to address user needs in smart environments because of the diversity of devices and functions users will want in such contexts. However, despite some promising technologies, tools and techniques, they seem to need to be better framed or integrated in order to provide their full potential. Finally, the need for configurability, personalization, tailorability (all used here as synonyms) seems to be a crucial feature for AT, more than a desirable quality, but one that can substantially determinate its success. In all the above mentioned papers in the last sub-section (AT-Ubicomp intersection – Section 3.3), the researchers report either the need to adapt the technology to different users' needs and characteristics, or the impossibility to find a unique design solution that was preferable by everyone. The need for more configurability is mentioned. However, very few is said about what this configurability really is and how it is instantiated using the technology being researched. Even when a single equipment is being studied, what to configure and how to do it is usually not made explicit.

These aspects will be discussed later and some of the work that we discussed in this section will appear again along our text, as they served as inspiration for some aspects of our design in some cases or supporting references in others. We shall reference appropriately whenever this is the case, as well as others references we used along the way.

4
Research approach

In this section we describe our research methodology, as well as the main reasons that lead as to choose it. We begin by presenting our initial research questions, following by the explanation of our choice of qualitative methods to investigate it. Then, we discuss our choice of selecting action research in our specific context of work, following by the description of the main subjects who participated in our research. Finally, we briefly discuss the ethic aspects involved in our research, in order to support it from the ethic point of view and to provide some guideline to those who may need to conduct work in similar circumstances.

4.1.
Research question(s)

When we look at the domain of AT, one of the greatest challenges is the variability we find in users characteristics and needs. In Figure 2 we illustrate that by showing some products that do, most of them, the same thing: they are hardware buttons with many different colors, sizes and activation pressures that the manufacturers build to try to address the fine level of adjustments and personalization that are usually necessary for a disabled user to successfully use an AT adapted mouse, for example.

Figure 2 – AT retailer booths at a national accessibility product fair. Most of the buttons above (left picture) are single on-off switches to be plugged in other AT devices, like adapted mice or joysticks (right picture).

As a starting point, we thought that *the ability for the user to adapt his or her own technology may have the potential to improve the user experience and the quality of the products of AT (and of the development of the products)*. However, before engaging in such endeavor we must answer questions like: what is configurable AT? What does AT mean to users (and to people around them)? There are, at least, two ways of defining AT: one is more technical, concerning the technology and its functions, as in the U.S. (United States (105th Congress), 1998); the other focuses on the disabled person, emphasizing the role of AT as an equipment for social inclusion, which is the case in Brazil (BRASIL, Presidência da República, 1999). This work follows the second definition and explores issues beyond functionality and technology that influences the design of both. We conducted a case study with a single tetraplegic participant who controlled some devices using an AT platform operated simultaneously by gesture and voice interaction in a smart home environment.

Also, we wanted to explore some other related questions:

- From the perspective of Ubicomp, how can we build an AT infrastructure based on smart devices and smart environments using the currently available technology? It seems obvious the potential that such technologies have in this area through the possibility of using mobile devices and wearables in an integrated manner to provide access to the environment for a user with functional limitations. But how can we further investigate interaction issues, mobility and connectivity in real contexts of use?
- Finally, EUD allows for customization and extension of a technology by the end-user. However, we see at least three issues to be further explored in our context: 1) Ubiquity: beyond the customization and extension of computer desktop programs in the traditional sense, EUD has been following the technological advances, first with the Web, then mobile phones, and now an heterogeneous pleiade of devices, some said to be smart, cohabiting together and with people in the same space. How to apply and evolve the existing EUD techniques and technologies seems to be a big new research challenge to be addressed in this area; 2) "End-User": who is the end-user of AT? Often, this technology will not serve a single user, but a group of people around a (temporarily or not) disabled person. This is especially true in cases of severe

disabilities, where the degree of intervention of family members and caregivers in the lives of the disabled is quite high, and often a matter of survival to them. Possibly, some configurations might be done by the disabled users, others by their caregivers and family. Certainly, everyone will feel to some degree and in some way the impact and consequences of these; 3) "Development": this concept is usually associated with computer programming or, more broadly, with software development. Historically, the software is thought to be responsible for the behavior of a computer whose form – the hardware – has previously been defined and on which little (or nothing) it can influence. Traditionally, the two aspects – form and behavior – are studied apart from one another, and some pre-defined interaction devices play the role of sensing the “physical” world's information (the form) to another “symbolic” (the behavior), and vice versa. But the interest in tangible computing and its applications has been growing and, in the case of AT, the *form* and *behavior* play a key role in the function and utility to be provided. Therefore, how can the EUD concept be extended to support changes and extensions of both, form and behavior, by the end-users?

Our research aims to investigate these questions from an empirical point of view dealing with real users in actual contexts of life using configurable AT prototypes.

4.2. Methodology: qualitative research

In research on disability, qualitative methodologies have emerged as one of the most important tools for understanding the complexities of functional limitations in their social contexts (O'Day & Killeen, 2002). The researcher tries to understand the experience of the participants from an internal point of view of the context (*insider*) and, in doing so, he or she seeks to develop a firm understanding of the basic dimensions of the issues involved and often to go beyond conventional wisdom and preconceived notions. The result is that the findings are based on the realities of everyday life and provide the kind of knowledge that has immediate and practical use (O'Day & Killeen, 2002).

On the use of qualitative research in the Computer Science field, Filippo says that the argument in favor of using qualitative methods is that through these methods the researcher is able to have a thorough understanding of the system when operating in a complex environment. Through methods such as case studies and ethnography, the researcher observes the environment, conducts interviews, films, among others. By learning about the environment, it becomes able to identify the different variables involved, relate them to their context, discover intricate details and identify different interpretations of the same fact (Filippo, 2008, p. 31).

In general, we used a combination of HCI methods for the design and evaluation of the system, most of which are well described in (Barbosa & da Silva, 2010). We used interview techniques and discourse analysis to collect and interpret the data, which can effectively capture and disambiguate accounts of the user experiences even when the user, intentionally or not, does not make it explicit (Light, 2006). In addition, participant observation provides the researcher with a proper sense of how is it to be the other, so that the researcher can access the real user experience by building empathy (Wright & McCarthy, 2008).

Data was collected through researcher's notes (“research diary”), photographs, audio recordings and transcripts (interviews) and videos (where applicable), always with the consent of the participants. In some cases, we also used a Capture & Access System (CAS platform) developed here at PUC-Rio, which provided a good infrastructure for qualitative research by enabling a complete video capture and subsequent analysis of the scene observed from different angles (Brandão, et al., 2014). From the scientific point of view, these data formed the empirical material and evidence of our research. As usual in this type of qualitative research, where one cannot control the conditions under which the data are collected, nor guarantee their reproducibility, to ensure theoretical and practical consistency of our research, details of the collection process and evidences will be described in the following sections (see research cycles – Section 5), so that readers can form their own judgment about these.

4.3. Action research

The term “action research” was introduced by Kurt Lewin in 1946 to denote a pioneering approach toward social research which combined generation of theory with changing the social system through the researcher acting on or in the social system. The act itself is presented as the means of both changing the system and generating critical knowledge about it (Susman & Evered, 1978). Among the proposed qualitative methods to carry out research about the use of computer systems in real environments, action research is one of them (Gerosa, et al., 2010). Action research combines both action and research within the same process and aims at generating knowledge by improving practice, and improving practice by the application of knowledge (Anderson & Herr, 2005). Typically, this implies researchers participating in the intervention or activity studied, and simultaneously evaluating the results. The advantages are firsthand experience, and the possibility to apply theory to practice directly. Disadvantages are the limited generalizability and the laborious efforts required for conducting action research (Tetteroo & Markopoulos, 2015). According to (Kock, 2013), action research is a generic name used to refer to a set of research approaches that have some characteristics in common, namely: in action research the researcher usually tries to provide a service to a “customer” and, at the same time, increase the body of knowledge in a particular domain. Also according to him, in the context of technology, it can be the study of how the technology is applied in the real world and the practical consequences of the action supported by technology. A typical example is the investigation of introducing a new technology in a context of use, while studying its effects in this context. The emphasis may be on the design technology, the empirical evaluation of the effects of technology, or in both aspects.

Action research allows the researcher to start from a particular problem identified in a real environment, and that the researcher act and be part of the researched environment, reporting his impressions of the problem and the solutions investigated. The aim is to advance the theory working in practice, which is done through actions in the context of the studied problem. The focus of research is on understanding the problem and the actions taken to resolve it within a particular real environment and not in the verification of a general hypothesis in a lab environment. In addition, action research allows researchers and “researched” to collaborate in order to understand a problem, the proposed actions to address it properly and the effect of these actions (Filippo, 2008, p. 25 et seq.).

In this research we sought to evaluate technological tools being designed and developed through the investigation of how users, in their contexts, use and are influenced by them as well as considering their collaboration on the design, what makes action research suitable for the purposes of this work. We also did an ethnographic study during the research, which is suggested and advised in qualitative studies (Neves, 2006). Despite the participatory spirit of considering user collaboration on the design of technology, we took the action research approach instead of participatory design (Muller & Kuhn, 1993). Although both approaches have similar participatory traits, they have different strategies and goals for doing so (Foth & Axup, 2006). More than the design of a technology per se, our goal is to build critical reflection, evaluation and informed action, that fits better into the broader and more opened action research framework.

Action research is typically performed in iterative cycles that successively refine the knowledge acquired in previous cycles. The execution of several cycles is seen as a way to increase the rigor of research, since it passes through new critical review in each cycle, that enables find errors, inconsistencies or biases previously not identified (Kock Jr, et al., 1997). Action research cyclical process comprises five phases: diagnosing, action planning, action taking, evaluating, and specifying learning as observed in Figure 3.

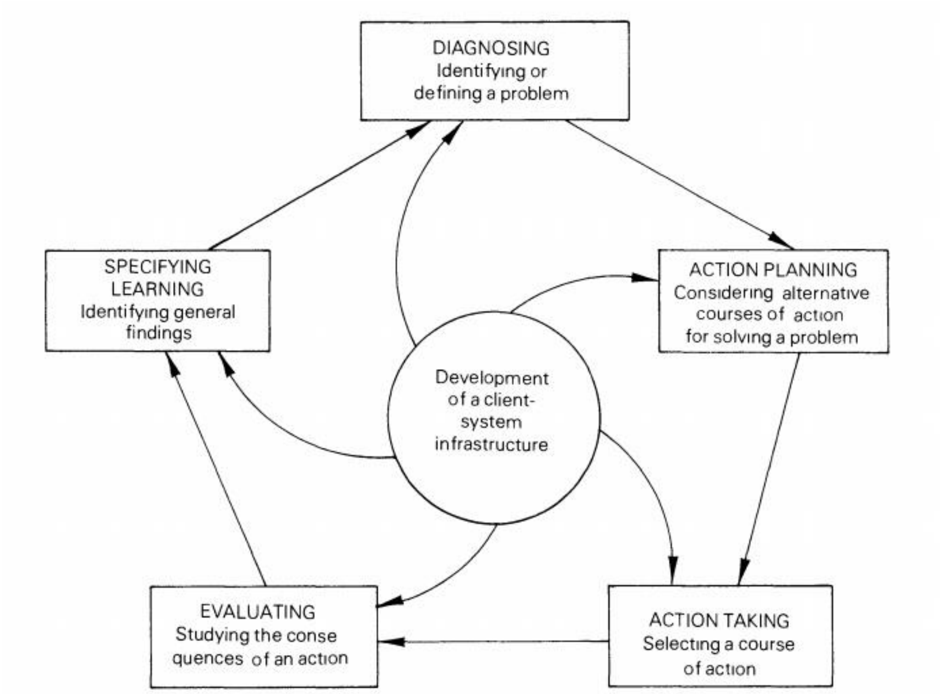

Figure 3 – The cyclical process of action research (Susman & Evered, 1978).

Usually, all five phases are considered to be necessary for a comprehensive understanding of action research. However, action research projects may differ in the number of phases which are carried out depending on each research goal and circumstances (Susman & Evered, 1978). The diagnosing stage involves the identification and definition of an improvement opportunity or a general problem to be solved in the client organization. The following stage, action planning, involves the consideration of alternative courses of action to attain the improvement or solve the problem identified. The action taking stage involves the selection and realization of one of the courses of action considered in the previous stage. The evaluating stage involves the study of the outcomes of the selected course of action. Finally, the specifying learning stage involves the study of the outcomes of the evaluating stage and, based on this study, knowledge building in the form of a model describing the situation under study. In the case of this dissertation, the research was conducted between 2014 and 2015 and we carried out two action research cycles.

4.4. Participants

The involvement of participants is a common practice and widely used in HCI researches (also called "subjects", usually the "users" of some technology under investigation). The objectives and focus of research vary around conducting a focus group, a collaborative design process, a controlled study, or an ethnographic research, but almost invariably require the involvement of people at work (Lazar, et al., 2010, p. 368).

When doing research involving disabled people, it is even more important to directly involve the users:

> “The goals of HCI research on users with impairments are the same as research with other users, understand the phenomena surrounding computer interfaces and usage patterns. Because the users have a complex story, it is important to involve those individuals in HCI research, design, and evaluation. You can't just take guidelines from the research on interface design for people with impairments, and you can't just take proxy users that represent the users with impairments. You must work with users with impairments themselves.” (Lazar, et al., 2010, p. 400)

At the same time, there are practical difficulties in working with this population of users:

> “Finding a suitably large participant pool can be particularly challenging for research involving people with disabilities. In addition to being an often-overlooked segment of society, people with disabilities often face significant challenges in transportation, making trips to research labs difficult. Studies with these users are often smaller, tending towards observational case studies with two or three users, rather than controlled experiments.” (Lazar, et al., 2010, p. 372)

And thus the scientific community has been tackling this issue:

> “The generally accepted approaches for dealing with the issue of access to appropriate participants for research focusing on users with impairments are small sample sizes, distributed research, and in-depth case studies. Choosing the most appropriate approach will depend on the nature of the research questions.” (Lazar, et al., 2010, p. 401)

What we conducted was an in-depth study, investigating a small population of participants involved all together in a very specific context of life, as we describe in the following section.

4.5. Research partner

The circumstances led us to a very particular real scenario: a graduate student at PUC-Rio learned about Beauty Technology – a technology being researched in our laboratory (Vega & Fuks, 2013) – and asked the authors to prototype a solution to improve his living conditions using this technology. The interested party is male, 33 years old at the time and is tetraplegic due to an accident suffered more 10 years before. He has no movement below his shoulders. Still, he has a very active life: he graduated in Business Administration and then got a Master's degree in the same area. His demand led us to perform a specific research on his real context of life, involving the technologies presented here and with him being the main user thereof, with the ultimate goal of improving his autonomy and the quality of interaction with the world around him.

From a human point of view, nothing better than perform a work whose result has the potential for a clear and immediate positive impact in someone else's life. From a scientific point of view, this is a real scenario of functional limitation that would allow us to investigate issues that would be impossible to replicate in a laboratory. From a practical point of view, we have a research partner quite willing to collaborate because of the benefit that he envisions that the research can return to himself.

4.6.
Research ethics

The research protocol of this project was submitted to and approved by the Ethics Committee of PUC-Rio. It presented the broad lines of research and the critical points about the ethics of this study. We provide it here as an attachment to this dissertation with the dual purpose of: first, give the reader the appropriate evidence of the ethics evaluation of this research what, we think, can contribute to its reliability; and second, offer some practical support to those who may need to conduct research studies in similar circumstances (see Annex I – Research protocol).

5
Research cycles

In this section we report on the two action research cycles we did. We describe them using the five action research cyclical process phases (see Section 4.3): diagnosing, action planning, action taking, evaluating, and specifying learning. However, before engaging in the action research itself, we needed to gain initial understanding on the domain we were targeting.

We initially did an ethnographic study conducted for approximately six months (starting by January 2014) which sought to define a feasible scope of work in terms of user needs, effort and complexity. During the first month, we had weekly meetings with him at his home, where we interviewed him and become acquainted with everyday situations in his home environment and how he performs his academic and professional activities. His daily routine includes studying and researching (as a post graduate student, this is currently his main professional occupation), healthcare activities (including daily nursing procedures, weekly physiotherapy and regular visits to therapists, physicians and doctors) and leisure and social activities, which includes watching TV, shopping, creating his own cooking recipes and going out with family and friends. He has two professional caregivers who take care of him every day alternately, by turns, and usually counts on the support of a parent by night occasionally. Normally, he is seated down on his wheelchair (not motorized and conducted by a caregiver around his home and in all the places he goes) most of the day, from where he does most of his activities. However, sometimes he is lying down on bed all day, as is the case when a caregiver is absent, and he is accustomed to work and do things in that position too.

As we said before, he graduated in Business Administration and then got a Master's degree in the same area. Both things happened after he got tetraplegic and were made easier after he started to use the computer unassisted. This was possible when he was suggested by a tetraplegic friend to use a software called Motrix to voice operate his computer. Motrix is a free tool for voice operating

Windows PCs which was targeted to be used by tetraplegic users (Borges, 2002). This tool enables a tetraplegic user to perform regular computer activities by means of voice commands that does the mouse and keyboard operations, like moving the pointer on screen, clicking and typing keys. It enables him to navigate the web, read and write emails, write essays and papers in MS Word, use the Excel and prepare presentations in Power Point by himself. He usually only needs a headset, someone to put it on him and to accommodate him in front of the computer for that. Participant says that Motrix does present some usability drawbacks and that the lack of upgrades (the latest version is targeted to Windows XP) often blocks him from upgrading his computer to newer Windows versions, or to different platforms, like Mac OS. However, this software stands as the main tool our participant uses on a daily basis and he have been using it continually for more than ten years by now.

During this period, we also researched on the big picture of Assistive Technology commercially available in the country and worldwide, as well as about it on related scientific literature. It gave us insights about possible solution paths. Altogether formed our initial knowledge of the user needs, general requirements and possibilities for a technology that could support our participant in his daily life. After that, we kept contact with him at more sparse intervals, approximately once every month, to keep ourselves updated and himself informed and motivated about the project, as we took the time to build our first prototype.

5.1. Cycle 1 – First prototype

On this first cycle, we aimed at building a first working prototype based on we have learned so far. Despite the availability of commercial AT equipment for motor impaired users, we find few targeted to severely impaired users and none to enable our participant to operate home appliances, like a TV for example. Most of the equipment we have found were adapted keyboards and mice to be used together with adapted switches (Figure 4). Most of these are targeted to users with motor coordination problems, as caused by cerebral paralysis, or cognitive limitations. We also found some eye gaze sensors but those were usually proprietary solutions and specifically designed to be used only with computers and tablets, despite they are usually expensive solutions. So, we decided to build our own prototype that would allow us for more experimentation and less early commitments in any design direction. Additionally, we wanted to enable him to use other devices besides the computer, which none of the solutions we found address.

Figure 4 – An adapted mouse (left) and an accessible switch (right) to be plugged in it. The mouse and the switch use a standard P2 plug, which allows the switch to be exchanged by different models, which can better suit users' different preferences, kinds and degrees of disabilities (see Figure 5 below).

Figure 5 – A switch that can be used by a tetraplegic user. It is activated by head and shoulder movements: it has a soft sponge in front of it and a pin on its back that can be used to fix it to user clothes.

We then planned to develop devices based on IoT technologies to support his interaction with his home environment and to perform his school and professional activities. These should address at least some of the needs he values the most and, of course, should be possible for him to interact with.

5.1.1. Diagnosing

According to user abilities, we have identified three possible interaction modes, based on (Abawajy, 2009) and depicted in Figure 7:

- Voice interaction: the most natural mode, which he is already used to use and is practical in most situations;
- Macro-movements: head and shoulders movements;
- Micro-movements: eye and facial muscles and expressions.

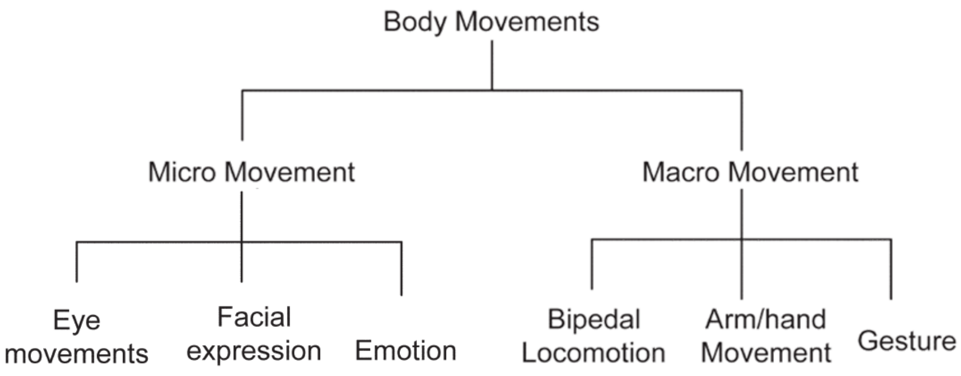

Figure 6 – Taxonomy of body movements for interaction in ubiquitous computing environments (Abawajy, 2009).

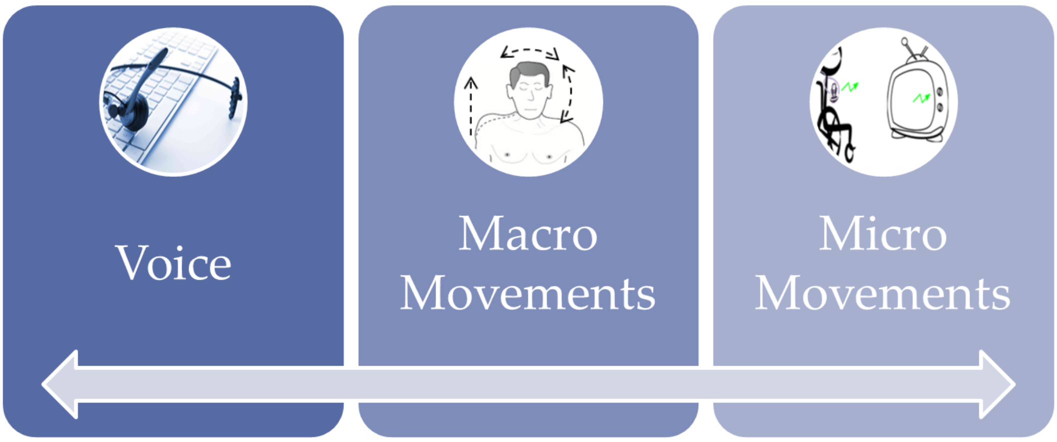

Figure 7 – Possible modes of interaction for a tetraplegic user.

In potential, all three possibilities could be experimented and we wanted to avoid premature compromises. We wanted a solution that were flexible enough to adapt to the particular abilities and needs of our participant in practice, which we only knew from observations and theory. From the design and engineering perspective, a natural approach for that would be the implementation of configurations, which also would support the investigation of our research questions.

5.1.2. Action planning

We did thought of building something like a trigger-action or IF-THIS-DO-THAT programming environment – which are considered to be powerful and "easy" enough to be programmed by the end-user (Ur, et al., 2014); (Barricelli & Valtolina, 2015) – where the technology could be customized by the user and his assistants and family. For example, we would like him to use this environment so that he could customize the outcome of each atomic interaction, in a first moment, and then, create his own combinations of commands, shortcuts to preferred actions, and the like. But first, we needed a prototype based on a technology infrastructure that he could operate.

As we were trying to introduce changes, we wanted to evaluate other modes of interaction than voice, which he already used. Thus we proposed the prototyping of a wearable for wearing on his head in order to sense head and shoulder movements. These movements would be the commands that would then be sent to the devices he wants to operate. Together with a wireless headset we bought, we would be able to sense most of the interaction possibilities, namely: voice, head and shoulder movements.

We also needed to provide connection between the interaction devices with what he wanted to operate. Based on his priorities, we chose to connect to his television and his computer, at first. Then, we included a mobile phone and a lamp. A mobile phone because we realized that it could be an intermediate connection platform suitable to aggregate intelligence and functions to allow for the platform to evolve. A mobile phone has high computing power, is considerably inexpensive and highly available and has plenty of resources, either applications, communities of users and development libraries, which are continuously evolving. It greatly amplifies the spectrum of possibilities, besides the fact that it enables him to use a powerful communication device by himself, something he has never done unassisted before. A lamp because although it is a very simple home appliance, it would allow us to give him a sense of other possibilities that we, as technologists, knew were possible.

Our prototype solution became more than a single equipment and turned into an AT platform proposal, as depicted in Figure 8:

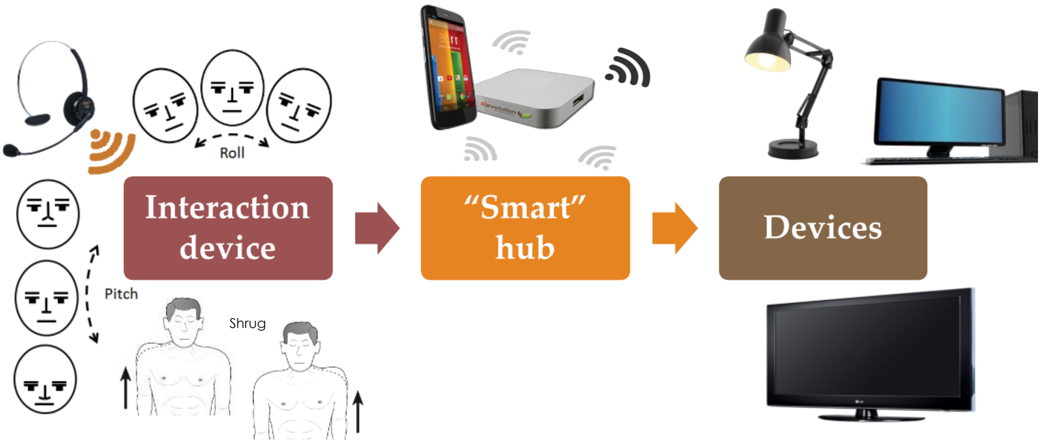

Figure 8 – Assistive Technology platform proposal.

This architecture has several advantages for the purposes we were seeking: it offers an accessibility bridge to multiple devices by means of the same set of user interactions, which leads to less training needs and a better learning experience to the user; it enables the communication and control with ordinary home appliances, even those not considered to be "smart" (meaning not connected to the internet and not endowed with autonomous behavior); it has a good cost-benefit because it can be built with inexpensive mobile and IoT components and eliminates the need for upgrading all home appliances at once. Finally, it offers a substratum where we could research configurations in different aspects, such as hardware and software, with a reasonable level of decoupling between parts.

5.1.3.
Action taking

We built the proposed AT platform. Our prototype was comprised by three parts (Figure 9):

1. An electronic cap – a wearable – that detects head movements and simulates a computer mouse. The cap can be plugged to up to four exchangeable switches

that are used to do the clicks. It communicates wirelessly to mobile phones via Bluetooth;

2. A dock station for Android mobile phones, which controls a lamp, a TV set and a wireless dual connection headset (switching between phone and computer);
3. An Android mobile phone, which is the central unit of control of the system and connects with the dock station via USB and with the cap via Bluetooth. The phone is equipped with an app designed to control each device individually, besides the native features provided by Android.

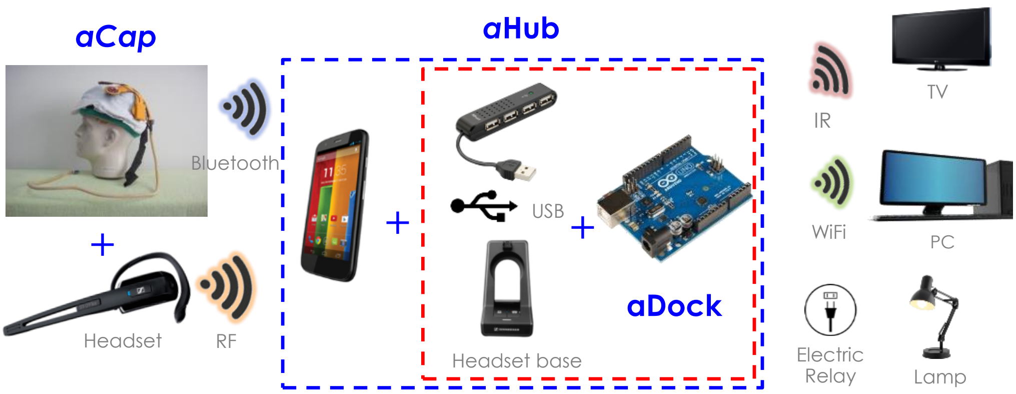

Figure 9 – Our AT prototype platform scheme. On the left, the interaction device, made by a wireless headset and a wearable we built, called aCap. On the center, the smart hub – aHub – comprised by a mobile phone with an app we developed and a dock station we built connected to it by USB – aDock. On the right, the devices the platform is able to connect: a TV set using infrared, a computer, using Wi-Fi, and a lamp, using a relay.

The following pictures show the devices we built:

Figure 10 – Details of aCap: three different views of the wearable, with a switch plugged on one of the four plugs on the back of the device.

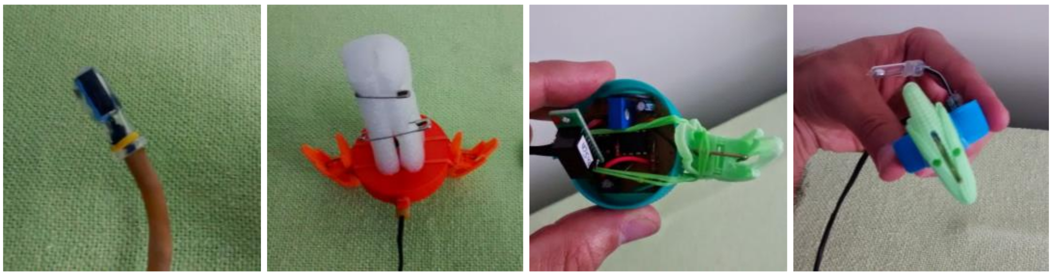

Figure 11 – Four accessible switches to be plugged in the cap. From left to right: one for the mouth, to be activated by bite, one mechanical for the shoulder, to be activated by shrug movement, another for the other shoulder, activated by shrug, but based on a distance sensor, and another also for the shoulder, but using a tilt sensor.

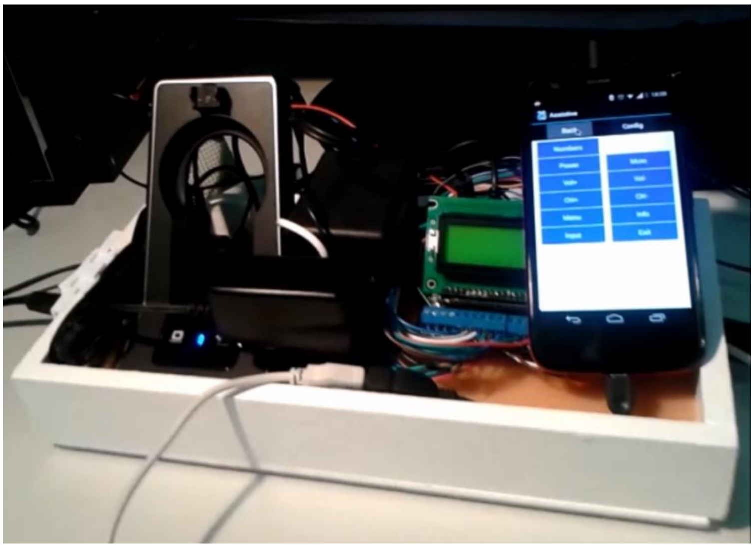

Figure 12 – Details of aHub, from left to right: the headset base station, the Arduino display and the mobile phone with our app.

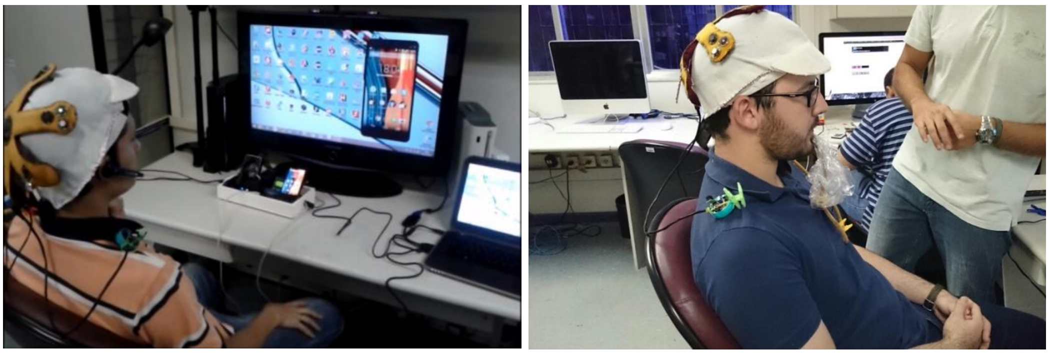

Figure 13 – Our AT platform prototype in use. On the left, a tester wearing the cap to control lamp, a TV set and a computer. On the right, we can see a tester using two of the switches: one in his mouth and another in his right shoulder.

At this stage, we have already built some configuration options to provide flexibility, such as the exchangeable hardware switches and the system modularity. For example, we could pick the switches that would work better for our participant, exchange an entire module of the solution without interfering in the others, and test for a mobile solution with reduced functions made by the interaction device and the mobile phone alone to be used at college or at work, without TV and lamp control. However, from the user point of view, we still had little idea of what should be configured and how. So, we decided to investigate our participant reaction in a first encounter with the actual instance of the technological support. We wanted to see if needs and opportunities for configuration would emerge and how this would come about.

5.1.4. Evaluating

We designed a study split in two steps. First, we presented the platform to the participant, taught him the basic operation and allowed some time for him to play with it. Second, we proposed a task scenario specifically designed to include multitasking: he would be working on the computer doing some generic activity (e.g., reading e-mail, the news, etc.) when a friend (a role played by another researcher) would call him unexpectedly to discuss a spread sheet in his computer. The session took place in the participant's home and lasted approximately three hours, including the interviews. Each step was video-recorded using the CAS (Capture & Access System) infra-structure, which allows for a complete capture and subsequent analysis of the scene observed from different angles (Brandão, et al., 2014). The researcher conducted and supported the participant during the session. At the beginning and at the end of each step we performed oral open-question interviews about his expectations about what was coming next and about his impressions on what he has just experienced, respectively.

5.1.5. Specifying learning

Our findings are based on two kinds of evidence: the participant's actions and behavior during the activity; and his utterances, during actions and when answering our questions. In the first step (technology introduction), we placed the cap on the participant's head, adjusted fit and position properly and tried out the different switches we could use. We quickly discarded two of them, because we noticed control problems and participant's emerging fatigue, discomfort and frustration. The other two were placed and adjusted in such a way they could be comfortably activated, which was noticeable and verbally confirmed by the participant. We connected all the parts, taught him the basics and then let him explore the equipment for some time on his own.

In the second step (task scenario), task switching and interleaving (triggered by us as part of the scenario) brought about interaction challenges that we saw and that were also verbalized by the participant during the interview. Switching the voice from the computer to the mobile phone and answering the phone doing a "swipe" with his head was the greatest issue. It took our participant several attempts to accomplish that, because of failure in one or another intermediary stage and confusion about moving the mouse pointer up and down. We observed some tension and anxiety, which was later confirmed by him in the final interview. The participant, however, persisted in the task, never asking to abandon it (which he could easily do).

This study revealed many configuration needs and opportunities. First, there were physical form and hardware options, like the size of the cap, the switches to be used, their positioning and fit to allow for comfortable use. Then, there were behavior configuration opportunities. In the interview, the participant spontaneously suggested the creation of shortcut buttons (hardware switches in this case) to allow for quick switching voice channeling from the computer to the phone. He also mentioned options for changing the behavior of the mouse pointer, like going up when he pitches down and vice-versa (the equipment worked opposite to his expectations). He even suggested the possibility to use head gestures like keyboard arrow keys, he referred to it as being a "more primitive" kind of control that could be easier for him.

One may argue that a better design for our AT prototype might improve his experience, which is true. However, the desired actions for any given task are subject to change according to the situation (for example, if he receives a call while watching TV at high volume) and the contingent access conditions to control buttons (limited by the range of physical movements the user can do). A configurable mechanism should provide means for defining shortcut actions using the available buttons (and combinations) that could be reconfigured according to context and task. Along this line, in the interview the participant referred to tetraplegic friends that he believes may act and think differently from him, for example, in the up-down head control preferences and in the ability to move the shoulders. We believe that a flexible system can effectively adapt to a broader population of users, addressing personal preferences and different abilities of each individual. We shall remember that our participant represents a “best case” user, with high motivation levels, given that he had anticipated the benefits of technology when he first contacted us in our lab. We could prove that during the study from our own observations on the effort he put to accomplish the proposed tasks and from the interview, in which he verbally said that he “wanted the thing to work”. Other tetraplegic user could find the whole apparatus too complicated to use or could not able to operate it due to a harder level of impairment. Some could not be able to use a shoulder switch, others could not be willing to use a mouth one, or even the whole cap. However, using *appropriate configurations* allows for adjusting the solution to each individual needs and preferences. Uncover the meaning behind what is supposed to be an appropriate configuration is our ultimate goal.

5.2.
Cycle 2 – New challenges

In this cycle we wanted to implement participant’s suggestions on the first prototype (besides other technical improvements we saw that were possible) and to investigate the interaction with other stakeholders and more about software (behavior) configuration applying EUD. For example, he suggested that he could operate the cap as keyboard arrows and we did implement a button to change between keyboard and mouse modes on the cap. We implemented a connection to computer through internet TCP/IP protocol to allow for remote controlling the computer from the same centralized unit, which was our platform main software in the mobile phone. This allows us to propose better configuration features, since a centralized unit of control can more easily provide the means to combine inputs and outputs from and to different devices in order to provide shortcuts, for example. Moreover, we also wanted to build a more polished prototype, a different form, maybe like a “smart headset” that could be more practical and discrete for him to wear. However, actual circumstances pushed us to a different direction.

On the first semester of 2014, our voluntary participant had a health problem and had to be hospitalized. While in hospital and for some time before and after that, he was prohibited from remaining seated for many hours, as he usually did. He had to spend most of the time lying down, what prompted us to new configuration and interaction problems on the prototype we were building.

We kept contact with him during the whole semester, more intensively after the hospital period. Despite the difficulties, he neither asked to stop the project, nor denied to talk to us, something that happened several times during this period, by email, phone and personally at his home. During the last month, we had weekly meetings, where we talked for hours about technology and life experience, discussing concerns we both share, as regular Brazilians and post-graduate students of about the same age. My impressions are that he enjoyed this talks, most of the time, as I did myself.

5.2.1. Diagnosing

Talking to him while he was lying on his side (is not only that he cannot sit down, but also that he must stay lying on one side and then the other for most of the time) made me see that the cap, a main part of our first prototype, was really useless in such a situation, what he confirmed stating that he was unable to move head and shoulders when lying on his side when I asked. In order to make another evaluation cycle with him using the technology (something we wanted in order to investigate other stakeholders participation and EUD), we would have to recur to other interaction techniques.

5.2.2. Action planning

Among the alternatives to address this new situation, we enabled the app to work with voice control. Other design alternatives like room camera gesture sensing, eye gazing, brain-computer interfaces or even mouth joystick were possible. Room camera gesture sensing (for example, using Kinect) would probably present challenges similar to what we were facing with the cap, due to his additional limitations in gesture movements while lying down. Eye gazing and brain-computer interfaces are indeed promising alternatives for interaction devices (Biswas, et al., 2013), but each method introduces its own particular issues that would require more time (and more budget, since these equipment are more expensive than the kind of devices we have been dealing so far) to be investigated properly. Mouth joystick was an alternative based on QuadStick (Davison, 2014), a recently released commercial product mentioned by him, but once again it would not be possible for us to acquire and test it in the remaining time we had. Voice enabling the platform have many benefits: first, our participant was used to use voice control, as he already does with his computer; second, it would be feasible, since we could build upon the Android speech recognition APIs, already available as native features of the mobile phone we were using; and third, it would enable us to finally implement and test some software behavior configurations, given that we build the mechanisms for user defined commands.

5.2.3. Action taking

A “WHEN-TRIGGER-THEN-ACTION” programming engine is considered to be the state-of-the-art of End-User Development for IoT (Barricelli & Valtolina, 2015). We decided to implement a voice enabled engine of this type in our prototype Android app to be used by the end-user to define his own customized commands in the form of “WHEN: I SAY THIS” (trigger), “THEN: SYSTEM DOES THAT” (action). Basically, we kept the mobile app software interface the way it was and added the new features. However, although it had changed little in its appearance, we did a lot of refactoring and reengineering into its code, the most important one being the decoupling of the device control operations from the app interface code, with the purpose of making any device control operation able to be invoked either by the app graphical interface or voice commands. The main app interface is shown in Figure 14:

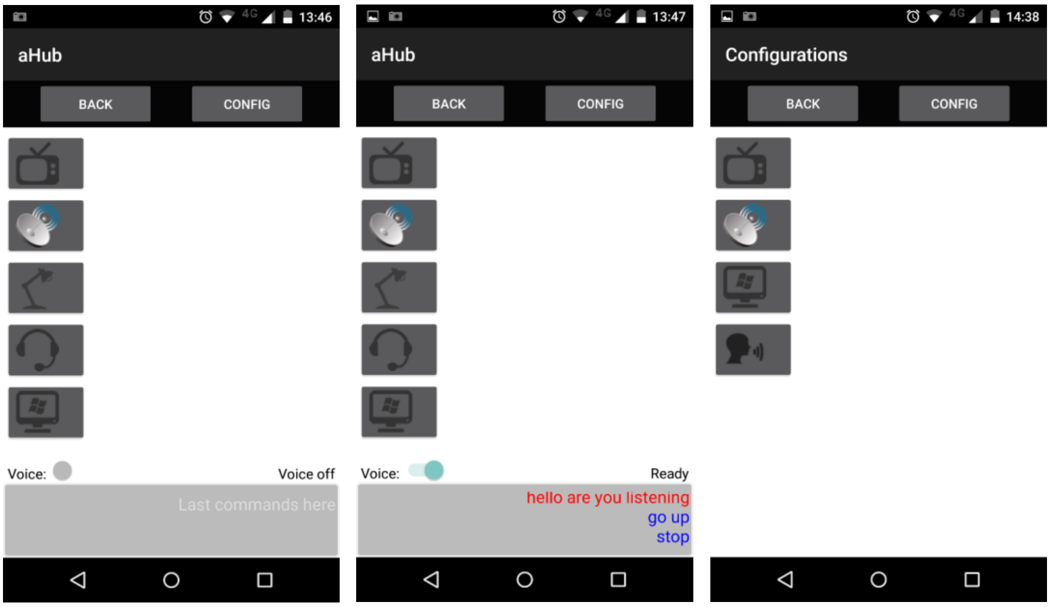

Figure 14 – Android app main screens: selecting the icon opens the respective device control screen on Figure 15 bellow. Above, in the middle screen, the voice recognition is on and the last received commands are displayed on the bottom box: recognized commands are shown in blue and not recognized ones in red. The configuration main screen is shown on the right, where selecting the icon opens the specific device configurations on Figure 16 bellow.

The other app screens perform device specific functions and configurations:

— One screen for each device that the platform is able to control, namely: a TV, cable TV box, headset and lamp, and we added a new screen for the computer control we implemented on this cycle (Figure 15). This last one presents the user with a virtual joystick for mouse control and a feature for text input, which could be entered by typing on the mobile virtual keyboard or by speech recognition, both being transmitted automatically to the computer;

— Four other screens for configuring each device (Figure 16). The TV and cable TV box configuration screens are practically equal and allows for the selection of different TV manufacturers and models (e.g., Samsung, LG, etc.), for changing the infrared communication protocol used internally. The computer configuration is used to setup the IP address and mouse speed. Finally, the voice commands configuration is used to define the voice commands which will trigger different device operations. The possible operations are predefined by the system capabilities (see Table 1), while the voice commands can be any combination of English words set by the user in the rule definition dialog box (Figure 17).

For the dock station, there were no changes at all, neither in the software nor in the hardware. We did some changes to the cap hardware and software based on his suggestions, but unfortunately due to all that was aforementioned, we did not test it.

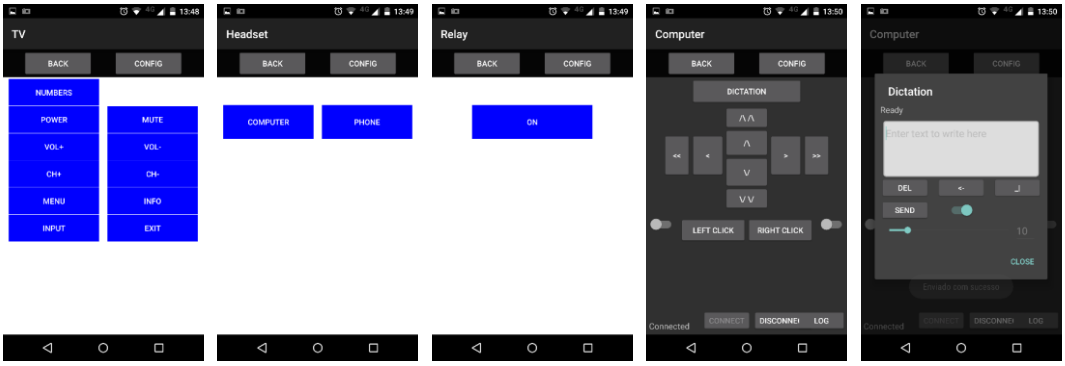

Figure 15 – Android app devices' control screens. From left to right: TV control (the same for the cable TV box control), headset control, lamp (relay) and computer control, with the text input dialog on the right screen.

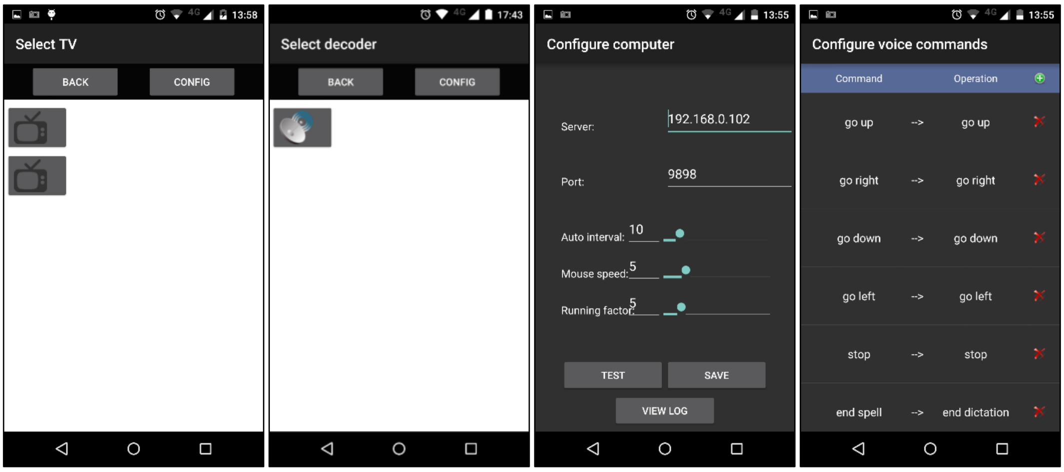

Figure 16 – Android app configuration screens. From left to right: TV model setup, Cable TV set-top box, computer and voice commands configuration.

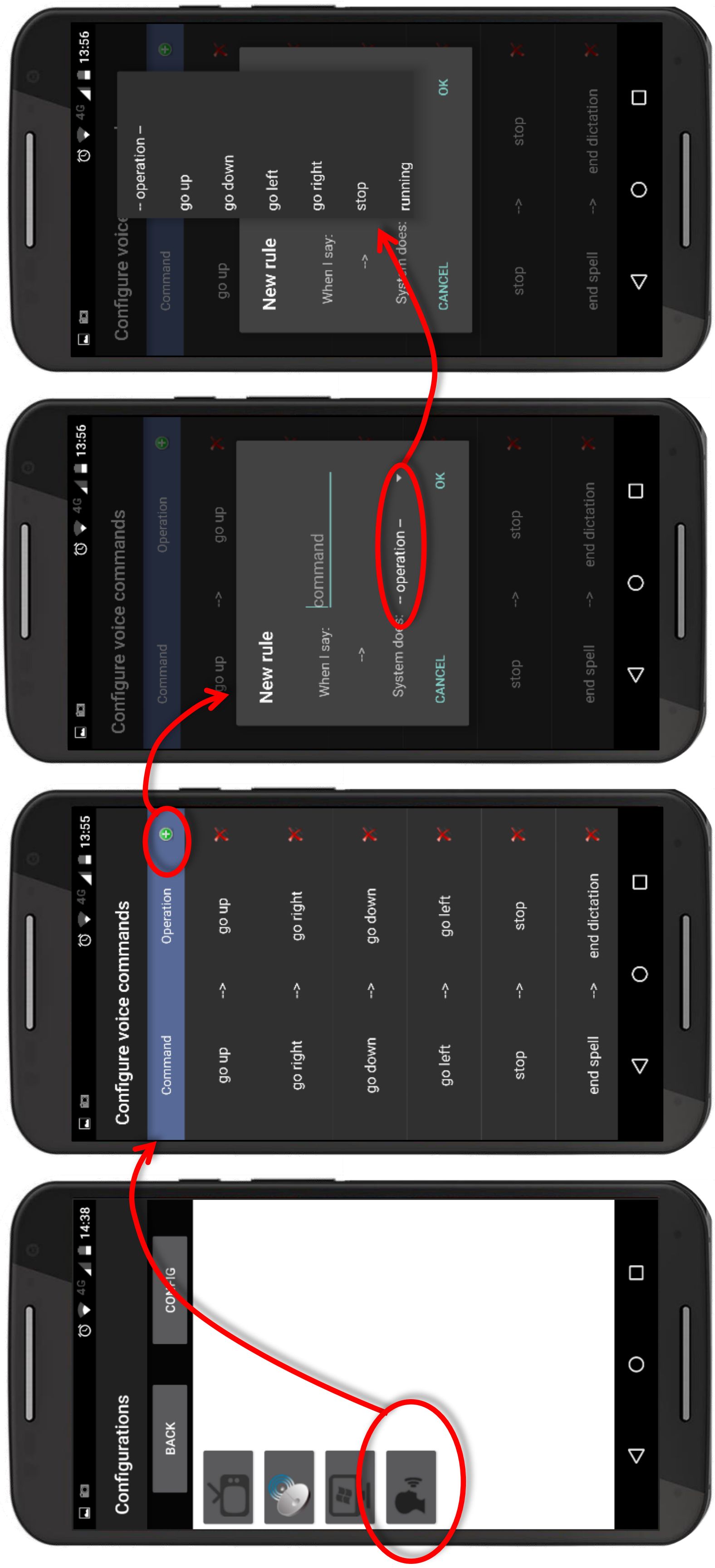

Figure 17 – Details of the voice command configuration: “WHEN I SAY THIS THEN SYSTEM DOES THAT” rule definition dialog box shown on the two screens on the right.

Table 1 – Device control operations.

#	Operation	Device	Description
1	Go up	Computer	Start moving the mouse pointer upwards.
2	Go down	Computer	Start moving the mouse pointer downwards.
3	Go left	Computer	Start moving the mouse pointer to the left.
4	Go right	Computer	Start moving the mouse pointer to the right.
5	Stop	Computer	Stop moving the mouse pointer.
6	Mouse press	Computer	Press the mouse left button.
7	Mouse release	Computer	Release the mouse left button.
8	Mouse click	Computer	Perform a left button mouse click with the left button.
9	Mouse press_right	Computer	Press the mouse right button.
10	Mouse release_right	Computer	Release the mouse right button.
11	Mouse click_right	Computer	Perform a right button mouse click.
12	Dictation	Computer	Starts the text input.
13	End dictation	Computer	Finishes text input.
14	Delete	Computer	Sends a Delete keypress.
15	Backspace	Computer	Sends a Backspace keypress.
16	Enter	Computer	Sends an Enter keypress.
17	Relay on	Lamp	Turns the relay switch on.
18	Relay off	Lamp	Turns the relay switch off.
19	Headset btn computer	Headset	Presses the computer button on the headset to switch the sound to the computer.
20	Headset btn phone	Headset	Presses the phone button on the headset to switch the sound to the phone.
21	TV power	TV	TV power remote control button.
22	TV mute	TV	TV mute remote control button.
23	TV volup	TV	TV volume up remote control button.
24	TV voldown	TV	TV volume down remote control button.
25	TV chup	TV	TV channel up remote control button.
26	TV chdown	TV	TV channel down remote control button.
27	TV menu	TV	TV menu remote control button.
28	TV info	TV	TV info remote control button.
29	TV input	TV	TV input select remote control button.
30	TV exit	TV	TV exit remote control button.
31	TV 0	TV	TV “0” number remote control button.
32	TV 1	TV	TV “1” number remote control button.
33	TV 2	TV	TV “2” number remote control button.
34	TV 3	TV	TV “3” number remote control button.
35	TV 4	TV	TV “4” number remote control button.
36	TV 5	TV	TV “5” number remote control button.
37	TV 6	TV	TV “6” number remote control button.
38	TV 7	TV	TV “7” number remote control button.
39	TV 8	TV	TV “8” number remote control button.
40	TV 9	TV	TV “9” number remote control button.
41	TV ok	TV	TV ok remote control button.
42	TV up	TV	TV select up remote control button.
43	TV down	TV	TV select down remote control button.
44	TV left	TV	TV select left remote control button.
45	TV right	TV	TV select right remote control button.
46	Decoder power	Cable TV set-top box	Cable TV power remote control button.
47	Decoder mute	Cable TV set-top box	Cable TV mute remote control button.
48	Decoder volup	Cable TV set-top box	Cable TV volume up remote control button.
49	Decoder voldown	Cable TV set-top box	Cable TV volume down remote control button.
50	Decoder chup	Cable TV set-top box	Cable TV channel up remote control button.

51	Decoder chdown	Cable TV set-top box	Cable TV channel down remote control button.
52	Decoder menu	Cable TV set-top box	Cable TV menu remote control button.
53	Decoder info	Cable TV set-top box	Cable TV info remote control button.
54	Decoder input	Cable TV set-top box	Cable TV input select remote control button.
55	Decoder exit	Cable TV set-top box	Cable TV exit remote control button.
56	Decoder 0	Cable TV set-top box	Cable TV “0” number remote control button.
57	Decoder 1	Cable TV set-top box	Cable TV “1” number remote control button.
58	Decoder 2	Cable TV set-top box	Cable TV “2” number remote control button.
59	Decoder 3	Cable TV set-top box	Cable TV “3” number remote control button.
60	Decoder 4	Cable TV set-top box	Cable TV “4” number remote control button.
61	Decoder 5	Cable TV set-top box	Cable TV “5” number remote control button.
62	Decoder 6	Cable TV set-top box	Cable TV “6” number remote control button.
63	Decoder 7	Cable TV set-top box	Cable TV “7” number remote control button.
64	Decoder 8	Cable TV set-top box	Cable TV “8” number remote control button.
65	Decoder 9	Cable TV set-top box	Cable TV “9” number remote control button.
66	Decoder ok	Cable TV set-top box	Cable TV ok remote control button.
67	Decoder up	Cable TV set-top box	Cable TV select up remote control button.
68	Decoder down	Cable TV set-top box	Cable TV select down remote control button.
69	Decoder left	Cable TV set-top box	Cable TV select left remote control button.
70	Decoder right	Cable TV set-top box	Cable TV select right remote control button.

5.2.4. Evaluating

Similarly to what we have done before, we split our study into two steps. Firstly, we presented the new features to the participant, taught him how to use it and asked him to play with it assisted by the researcher. Secondly, we proposed a scenario specifically designed to force collaboration: he would start to use the platform without all the voice commands being configured. He would then had to ask to one of his caregivers to change or add some voice commands according to his needs. Our goal was to evaluate the overall performance of the voice operation enabled platform, to get feedback, mainly about the voice command configuration feature, and also to investigate the collaborative configuration work, given that the user motor limitations make him need assistance more often than the average people.

The session took place in the participant's home and lasted approximately four hours, including interviews and breaks. Each step was videotaped using two cameras from different angles. The researcher conducted the participant and his caregiver during the session. We performed five oral open-question interviews: one with the participant before we started the first part; another with his caregiver, before we started the second part; another one with both the participant and his caregiver right after we have finished the second part; and two more with each one of them individually, at the end of the session.

5.2.5. Specifying learning

We started by showing the participant the computer control features, explaining he was supposed to operate it using the cap when seated down (although, unfortunately, he was lying on his side during the whole session). Then, we showed the voice control that he rapidly understood and immediately started to try to command the system himself, speaking the computer commands he was used to. The computer commands we built were strongly based on the Motrix software he already used. This software stands as a key reference to our participant and we also used it as a reference implementing the computer operations to work in the same way Motrix does whenever it was possible.

We had previously configured some awkwardly phrased commands to be purposely different from the Motrix interface (e.g., "move to the right" to stand for "go right"), something that was quickly noticed by the participant. We did that in order to highlight the voice command configuration feature, what has proved to be an effective strategy: he got disappointed when he spoke a known Motrix command that did not work, but then positively reacted when we explained why. He then confirmed his positive impressions on the final interview:

> *"Yeah, I liked the fact that you can customize the commands, it's kind of a "pre" customization, right, because it already has the commands, but you put the commands you want to say on the top of that command that already exists. I thought that was pretty cool. The Motrix, for instance, does not do that. I liked the thing about the television, the volume control and such... Although the volume didn't work, I think it was what I chose as a command that was bad, but there is an infinite possibility of commands, I can even use, like, "one" to go up, "two" to go down, something like that."*

He even asked for more advanced configurations related to this engine: during the first part of the activity (the researcher showing him the new features). As I showed the voice command configuration to the participant, he immediately asked me to add a command to launch Google Chrome, explaining that this was not possible in Motrix, because it always opens the Internet Explorer. However, I explained to him that in the current prototype version this was not possible, given that the available commands are restricted to “lower level” operations such as move the mouse, click, typing, etc. (see Table 1). He later confirmed his interest in the “upper level” operations:

> *“It has those more advanced commands that you were saying, but I also think it's a matter of configuration, that you can work in that commands and the like...”*

Interestingly, he thought it was a matter of configuration the researcher as the developer could make. I explained him it was not a configuration I could quickly do and that it would demand new code implementation for new features. (However, it was interesting that, from the user point of view, there is no noticeable difference, what made us think that, in many cases, program coding can be seen as nothing more than a behavior configuration by the developer.) It also evidences the usefulness and applicability of this EUD engine in such a context:

> *“Yeah, because it saves you time you do not have to move around with the mouse on the screen and stuff like that. So for example, one wants to open, let’s say, Google Chrome, or Internet Explorer, if every time one wants to open it one have to fumble up and down, whatever, there comes a time that one gets too lazy to do it. Then, one says "open Internet Explorer", "open Google Chrome", something like that ... In Motrix, one just says "internet", then it opens Internet Explorer. I thought that its failure is that it doesn’t open the system’s default browser, it is tied to the Internet Explorer. So if I want to define Google Chrome as primary browser when I say "Internet", it will open the Explorer, which I don’t use.”*

We think this statement shows another interesting EUD application in such a context: is not only that it enables the user to extend the system, but also that it would make him able to *fix* and *integrate* systems according to his needs. Google Chrome did not exist at the time Motrix was launched back in 2002 and probably, the system default browser configuration in Windows has changed throughout this period. Without upgrades by the Motrix team, the user had no alternative other than abandon the "internet" command at great cost. The more complex the ecosystem is (as is the case with the IoT systems), the more it is likely that such a thing happens. EUD features can help users cope with that independently of the continuous existence or upgrades of the system. Given that Motrix was his original choice and that he invested many hours to learn and train the system, he simply opted not to exchange the Motrix for another voice recognition system.

On the second part of the scenario (participant asking his caregiver to help him with some configurations), participant started by asking his caregiver to change practically all computer control commands to be exactly to ones he uses with Motrix. This was expected because, as we said, Motrix is his main interaction reference with the computer, a tool he has put effort in learning and becoming proficient at. His particular caregiver made suggestions to make the voice command configurations available in the computer, so that the participant could change them by himself. It was not that he was not willing to cooperate, but instead it shows a deep understanding and experience in dealing with the disabled participant, as we can see in the following interview excerpt:

> Caregiver: *Man, that is, to me, to operate it for him, to prepare the things for it to work, I found it easy, to operate the program, very easy. Just wondering if it will be functional for him, right, to operate the program. But in terms of... for me... that is, to put it to work for him is very easy, very, very easy.*
>
> Researcher: *What are your concerns when you say that? What are you thinking of?*
>
> Caregiver: *Dude, it's not up to me, because I'm here to work, whatever I have to do I'll do, you know? I don't know if he will have the patience, every time he needs* (something)*, to make the whole scheme work, you know? Because I see that it's not just to use a phone, it is not only that one puts the phone there for him to speak the commands, that's not all... There's this other device right here* (pointing to the dock station) *which is connected to the appliance and without it then I think it wouldn't work, right?*
>
> Researcher: *This is for controlling the television, it also controls the lamp, right. This is part of the work.*
>
> Caregiver: *I think that, man... If it was just the phone itself, or maybe instead of the phone it could be directly on his computer, I think it would be more functional, right? One has to get it there* (points to the dock)*, connect it, and etc., I don't know if he will have the patience to do it, right? I'll be here to help, whenever he needs, I'll help. But I think today, in the world we live today, things are so evolved, you have to do things in a way to get things done as quickly as possible, you know, because people do not have much patience to wait. I think the fact that one has to connect this device*

> *here* (pointing to the dock)*, then turn on the phone,… it is much more convenient he comes to me and talks like this, as he is with a nurse all day, I think it's much more convenient he comes to me and talks like this, "Tom, turn on the TV for me and tune into that channel." Or, turn on my, my, my ... air conditioning. If he needs to type something, he can come to me and talks like this, "Tom, can you type something for me?", Then I type it up. Sometimes, I type it, and maybe that I type it even faster than he speaking, you know? I think that, man.*

The participant was present during this interview and confirmed most of the things his caregiver said. During his interview, he also agreed with his caregiver:

> *"I, I thought, I thought it was cool, but I think that what Tom said, it makes sense to use the* (configuration) *controls in the computer."*

It seemed that both his caregiver and he had no difficulties in operating the system together, in order to perform the configuration changes we suggested. The participant did not give that many explanations to his caregiver, who quickly understood what was needed, and successfully did it many times. This was confirmed by both the participant and his caregiver when asked about the activity:

> Participant: *"I thought it was cool, and Tom, Tom is quite street smart. He, he... you know, I just do it once or twice, and he already knows how to do it by himself, without me having to explain a lot, you know? He gets it easily. If it was the other one* [the other caregiver that works for him would find it much more difficult to configure the equipment]. *Tom is "techie"."*
>
> Caregiver: *"Man, in terms of operating it, I found it was easy... Oh, for me it's easy because I know how to do it, I know how to deal with mobile, I tinker with computer, then it makes it easy, right?"*

Even though we are currently working with a single tetraplegic user, our research had to deal with all stakeholders from the very beginning: as a severely impaired user, he depends on his caregivers and family members to support him in most of the things he wants or needs to do, including the interaction with any surrounding devices. He usually counts on one professional caregiver who takes daily care of him during the day and family members who can occasionally support him out of this period. His condition enforces a situation where he needs assistance for performing all physical manipulation on the objects around him, that includes common tasks like moving himself and moving things around, preparing to a specific work, study or leisure activity, turning on a computer or any other device and changing their setup. This also holds to those devices that are assisting him, *i.e.*, the AT devices as is the case of the platform prototype. Its immediate consequence is that even though the AT targets a (disabled) main user, many other people performing different roles, functions and responsibilities will interact with it in order to fulfill the main user daily needs. In such context, AT is a component of a collaborative system. This will be true in most cases where the end-user depends on other person's help due to his or her functional limitation, which is especially true when dealing with severe cases, where the degree of assistance needed by the end-user is presumably higher.

6
Research wrap up

In this section we wrap up our findings from the research cycles, summarizing them in two main contributions. We took as a starting point that *the ability for the user to adapt his or her own technology may have the potential to improve the user experience and the quality of the products of AT (and of the development of the products)*. We investigated this from an empirical point of view dealing with real users in actual contexts of life using configurable AT prototypes. Along the way, we faced theoretical and practical challenges that lead us to a new stage of understanding of the problems that we tackled. We think this new understanding brings significant contribution to the knowledge of the field, uncovering aspects that seem not to be sufficiently studied yet. At this stage, our contribution is to propose a structure for organizing the AT configuration problem space in order to support the design of similar technologies. This structure splits into two aspects discussed in the following sub-sections.

6.1.
Dimensions for End-User Configuration

After investigating implicit and explicit AT configuration needs and opportunities we learned that we must address both hardware and software configuration, partly to be done by the end user, partly by the other stakeholders. As a result from our first research cycle (Section 5.1), we propose three dimensions for analyzing AT configuration needs and opportunities (Chagas, et al., 2015-a):

– The **psycho-social dimension**, concerning the different form and behavior factors that may be desired in different situations in a context-dependent way and determined by individual motivations and social environment. That includes: appearance and mobility, devices to be controlled, shortcuts for quickly performing functions, and end-user definitions of contexts, tasks or situations of usage. For example, the equipment to be used at home may be different from that to be used at school or work due to its appearance, portable abilities and devices to interact with. In the same way, figuring out the functions and how to perform them will probably be totally different in each context: e.g., there will be no TV at work, but the user may need to control a projector; using voice control is more convenient and practical alone at home, but not at the classroom or meetings;

– The **carrier dimension**, concerning the means by which a configuration will be done and the substratum where it will reside: whether it is a hardware, software or hybrid configuration and whether it is to be changed by the user himself or by the other stakeholders. That includes the fit of the cap, which switches and their position, that will have to be put on him by the other stakeholders; however, the outcome of a switch activation and the connections to other devices may be done by himself on the platform software;

– The **persistence dimension**, concerning the duration of a configuration, its timeliness and volatility: some configurations will be temporary, and some will last for a long time or even forever. For example, a user’s size and abilities to move his head and shoulders are unique, and will not change significantly over time, allowing for a persistent setup; however, tasks and contexts of use will stop making sense once the user changes activity, changes devices, and so on.

Design features will necessarily have to be considered from the perspective of more than one dimension. For example, the look feature vary between discreet and impressive in the psycho-social dimension (depending if the user is going to school or to a date), imposing changes in the carrier dimension (hardware). From the persistence dimension perspective, this configuration will be kept only for the duration of a date outing or a class. Then, the user will save it as a preset for future similar situations. From the example above, it is clear that these dimensions play complementary roles all closely linked to each other that cannot be considered separately during the design time in order to achieve the pre-defined goals.

After publishing (Chagas, et al., 2015-a), we received valuable feedbacks from the research community that shed light on the first and the second dimensions, leading us to propose a more precise set of dimensions. First, we realized that the psycho-social dimension was too broad, because, given that everything takes place in some psycho-social context, it does not help in our analysis here. We also understood that the carrier dimension was somehow confusing, because it mixed the concepts of means and actors of a given configuration. So, we decided to reorganize the dimensions: we renamed the persistence dimension to simply **time dimension**, to refer to both the time when a configuration is performed and to the duration for which it will last, because both things are closely related to each other (a configuration lasts until the next time it is performed); we sub-divided the carrier dimension into the **substratum dimension**, comprising the locus (hardware, software or both) where a configuration will reside, and into the **agency dimension** that describes who is responsible for performing the configuration. We understand that this new set of dimensions better separates the concepts, and at the same time highlights the collaborative aspect of the configuration process. We came about that throughout our whole research, observing his daily relationship with his caregivers, family and home employees. Apart from the user and the other stakeholders, we will have a larger spectrum of possibilities in this agency dimension including automatic configurations, where the agent is an automata on behalf of the system designer, and the designer himself, when releasing system builds.

The configuration dimensions we propose are depicted in Figure 18:

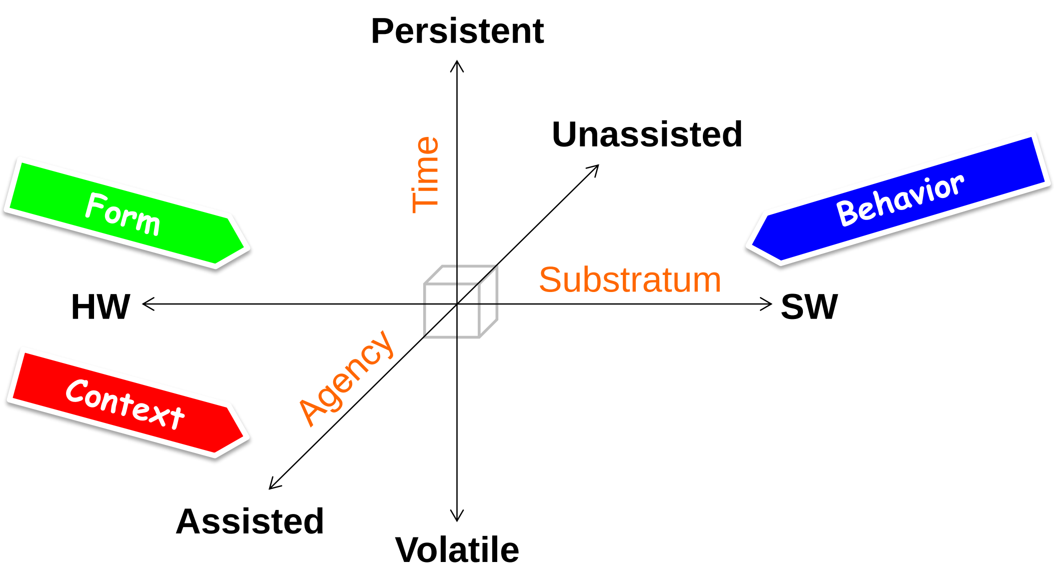

Figure 18 – AT configuration dimensions.

To the best of our knowledge, this characterization of the problem space has never been proposed and we believe that it is a starting point for incorporating configuration features into most AT systems. It should be used both as a tool for analyzing, exploring and better understanding AT users' experience, or as a classification to inform AT designers. In particular, these dimensions help identifying the techniques, technologies and approaches that may suit each configuration need of an AT system under design. According to the values of available options for substratum, time, and agency, the designer is able to decide which configuration features are to be provided and how. A configuration may be achieved via product builds (factory settings), soft and hard adjustments, parameters or EUD activities. Each one will make use of a specific interaction style that must be designed according to the real context of use the AT is targeted for. Designing a configuration from the different dimensions perspectives should improve the overall quality of an AT system, its robustness and scale of production, providing practical and effective means of AT mass customization by allowing the same technology to address different forms, behaviors and contexts.

6.2. Micro-meta-groupware

From the literature review we inferred that collaboration support is a common requirement in the AT domain: usually, collaboration will take place around the technology being proposed or used to the benefit of a main user – the disabled one. However, how this collaborative process takes place and how to support it is usually considered apart from the AT itself; in most cases it is not considered at all. Thus, in this work, we propose a conceptual scheme of an assistive technology groupware platform for users with severe motor limitations (Chagas, et al., 2015-b). Stating it precisely, our framework takes into account that such a technology demands and promotes a collaborative process around and about its configuration. For that reason, we named it *micro-meta-groupware*, a conceptual structure of a collaborative system around and about itself.

After investigating how multiple persons perform AT configurations (second cycle, Section 5.2), we realized that this process reveals very particular characteristics. The collaboration process will take place around the assistive technology, but it is also a collaboration about the technology itself, given that there would not be any collaboration if there were not AT systems to configure. It puts such AT in a position where it is, at the same time, the target and the support of a collaborative system. The former because it triggers a series of new activities that simply will not exist without it being there, such as wearing, fitting and adjusting a wearable device, like the electronic cap. The latter because any configuration can only happen in features previously provided by the technology itself, like its hardware and software adjustments. Once that is understood, we may think about how to better support these activities by applying the extensive body of knowledge of collaborative systems (Pimentel & Fuks, 2011). For example, this would include the appropriate mechanisms for allowing individuals inside the group to be able to configure different parts of the AT, both locally and remotely (from one's personal mobile phone or a web system, for example). At the same time, the main user must have the appropriate means to be in control for allowing and disallowing individuals' actions, asking for changes and blocking undesired interventions in the system. Finally, some of the configurations may change the system in more significant ways (e.g. a new software release or upgrade by the manufacturer), imposing significant changes not only to the main user, but also to the other individuals in the group that will have to deal with new demands to learn the new system features at some level.

Given that a single disabled user can be seen as a universe-of-one (Carmien, et al., 2005), all the persons around him represent a "micro" universe revolving around him and the technology. Within a small group of cohesive people, relationships are highly based on confidence and trust, including the professional ones, developed over time and on which depends, most of all, the survival of the main user. Somehow, everybody inside this group seems to be very conscientious about it, in a positive and not deluded way. Then, we identify seven different stakeholder profiles involved in this collaborative interaction:

1. The main user, the disabled subject to be supported;
2. Family members, who are emotionally (in good and bad ways) involved and concerned about his welfare;
3. Caregivers, both formal, such as professionals nurses, and informal ones, such as home employees;

4. People with similar needs, such as other tetraplegic friends, with whom he can talk about his problems and concerns at a deeper level of empathy and mutual understanding;
5. Friends and colleagues, who occasionally and unwittingly become helpers and supporters in daily social situations such us group meetings and group work;
6. Therapists and doctors, whose opinions from the clinical and medical perspectives poses a distinct level of importance; and
7. Technical experts who may have knowledge of tools and facilitate many decision making processes regarding technology, such us the developers/specialized manufacturers, retailers and assistive tools service suppliers.

Each person is a *de facto* potential user, many times unwittingly, bringing certain requirements to the AT configuration process, and to the design thereof. Moreover, each stakeholder is a designer inputting configurations that shape the system, each one having different motivations and levels of engagement, generating changes and change requests to be addressed with different levels of priorities.

7
Final discussion and conclusion

The aim of this dissertation is to investigate the design, implementation and user experience of configurable assistive technologies. We recurred to EUD and IoT technologies in order to promote advance of the AT domain. That was done by means of a case study in which we developed and evaluated an AT prototype to support a single tetraplegic user in his daily activities. Throughout two action research cycles, we investigated interaction and design issues and came to propose a structure for organizing the AT configuration problem space.

Section 1 introduced our main goals, motivations, contributions and the methodology for this research. It also clarified the researcher's bias, a software engineer, which shaped the development of this research. In Section 2, we presented an overview about the main topics of our research, some scientific and technological background, as well as the main motivations in investigating them together. Section 3 provided a literature review to give the reader an overview of the state-of-the-art in the intersection of AT, EUD and Ubicomp. Section 4 outlined our research approach and the motivations behind it, as well as the circumstances and stakeholders who motivated and guided our work. Section 5 reported the two research cycles we went through, following a typical action research cycle template. In Section 6, we proposed a conceptual structure for organizing the AT configuration problem space.

Now we present our finals considerations highlighting our main contributions mentioning other topics that influenced and can be influenced by our work. We illustrate the usage of our contributions and point out to the future work that we believe are of most relevance to the continuity and evolution of the topics presented below.

7.1. Applying the dimensions

In Section 6.1 we proposed three dimensions of AT configuration, namely: the substratum dimension, concerning the locus where a configuration will reside (hardware, software or both); the time dimension, concerning when a configuration is performed and for how long it will last (ranging from volatile/frequent to persistent/rare); and finally, the agency dimension, concerning who is responsible for performing a configuration (whether the main user or another stakeholder). These dimensions should be used both as a tool for analyzing, exploring and better understanding AT users' experience, and as a classification to inform AT designers. In order to better illustrate their usage and support their validity, we decided to apply them to the AT platform prototype we developed, as shown in Table 2.

Table 2 – Characterization of our AT platform prototype applying the configuration dimensions: substratum, time and agency.

What			How		
Module	**Configuration**	**Options**	**Substratum**	**Time**	**Agency**
aCap	Switch(es) choice	Mouth button, mechanical shoulder button, distance sensor shoulder switch, tilt sensor switch	Hardware plugs	Once before first use	Helper
	Cap appearance	White cap or blue wool cap	Hardware (exchangeable through eyelets in the electronic set)	Before every use	Helper
	Fit on his head	Continuous fit	Elastic band with buckle	Before every use	Helper
	Operation mode	Mouse or arrow keys	A hardware button on the cap	Before first use *or* on task change	Helper
	Sensitivity (to head movements) and speed	Continuous range	aCap software	Once before deployment	Developer
aPlatform	Modules to use	Cap + dock + mobile, cap + mobile or mobile + dock	aCap, aDock and mobile phone	Before every use	Helper
aHub	Voice commands	Any English word	Android app	Before first use (subject to later adjustments)	User or helper

Table 2 shows revealing aspects about our prototype and our case study. Firstly, it shows that the cap was by far the most configurable piece of technology we built. Unfortunately, it was not evaluated with the user in the second cycle due to the circumstances we faced regarding participant's health, as described in Section 5.2. It was impossible to investigate the combined use of voice and head gestures, and how the user would react when having the option to configure something with the help of his caregiver or by himself, as would have been the case if he could use the cap. It shows that our research is unfinished, reinforcing its alignment with the action research methodology. Given that we had to adapt to actual circumstances, we gave up of evaluating the cap in the second cycle, even though there was a considerable amount of investment in building it. Secondly, we learned from the agency dimension on Table 2 that most of the configurations on our prototype were (unwittingly) built to be set by someone helping the main user. Analyzing it *a posteriori*, we understand that this is due to the technology we built, which asks for different hardware configurations. It influences the user experience, as pointed in our second evaluation when the caregiver explicitly states his concerns about all the things that have to be set implying that the main user will find it easier just to ask somebody else to directly do something for him, instead of using the technology (Section 5.2.5). That suggests that we should invest in migrating the hardware configurations to software. Sometimes we did not do it due to lack of technical competence and time to invest in it, as was the case for controlling the cap operation mode (it was easier for us to place a new button on the cap for that purpose than to create a software configuration in the mobile app, for example). However, exchanging a plug or controlling a buckle in the cap's elastic band, for example, do not seem to be trivial software controlled tasks. Despite the recent advances in communication and sensing technologies that we have been witnessing, actuators for physical objects seem to lag behind both in simplicity and costs, suggesting this is an area where we should intensify our investigations. Researches like the "El-e" assistive robot we mentioned in Section 3.3 is just one of many possible paths to explore. When we think of AT as a compensation for an ability that a person does not have, we need technology that can move and manipulate the physical environment, which is precisely the missing ability for motor impairments.

Another consequence of the agency dimension distribution is that it fosters collaboration, frequently demanding the participation of one more user besides the disabled one. In the following section we discuss collaboration and its implications in such context.

7.2. Exploring collaboration

The researches described in the Section 3.1 (EUD-AT intersection) took a collaborative approach to overcome users' limitations: in the first and the second, due their functional cognitive limitation (Carmien & Fischer, 2008); (Lewis, 2007); in the third, due to their lack of know-how in web developing (Bigham & Ladner, 2007). From a systemic perspective, there is not much difference between the two cases: one helps the other with one's complementary abilities. It seems a promising approach to better explore this path in the AT domain, where end-users usually depend on other's people's help due to their functional limitation, which is true especially when dealing with severe cases, where the degree of assistance needed by the end-user is higher.

In Section 6.2, we envisaged the advantage of having the micro-meta-groupware framework for supporting the collaborative configuration process around AT and the design of appropriate technology. We also consider this framework to be related to Meta-Design and, more broadly, to Cultures of Participation, in which everybody is provided with the means to participate and to contribute actively in personally meaningful problems through socio-technical systems (Fischer, 2011). Medicine 2.0 (Eysenbach, 2008) proposes a series of promising applications that leverage socio-technical systems to support personalized needs in the healthcare domain; but how to support all users' needs and participation in such a context needs further investigation. In the AT domain, accessing and addressing the variations in users' unique skills and needs require an intimate knowledge of the user that, usually, close relatives and caregivers are in the best position to provide (Cole & Dehdashti, 2006), making them *the real* domain experts. Our framework aims at promoting that *the real* domain experts engage in the design, adoption, and adaptation of technologies to their needs and in the collaborative knowledge creation. However, AT is a sensible domain because it has the potential to positively affect a user’s life in more significant ways, but also to introduce higher risks of physical and psychological harm. We should further investigate how it should be done in such a way that: (1) the system effectively and safely support the main user final goals and needs; and (2), the system supports the participation of all stakeholders at their desired level of engagement. For example, equipment may break or malfunction leaving the user without other possible alternatives and increase the dependence between group members because of the technology. To avoid undesired configurations, main users should have the appropriate means to manage the group, while other stakeholders are able to manage their desired level of engagement. The former will have to manage group permissions and access to information in order to ensure the equipment usage and his own safety. The latter will have to deal with equipment details (either by professional, personal or social reasons) that he or she might not able or willing to learn.

Kintsch & DePaula (2002) propose a framework for the adoption of AT which identifies the following participants in the adoption process: the users, those involved with the user on a daily bases (caregivers), designers and AT experts. In order for adoption to occur, each of these parties must bring certain attributes to the process. Together, a complex and often difficult collaborative process of designing, selecting, personalizing, learning and integrating must be accomplished. In this work, we were concerned mostly with the collaborative process where many configuration activities take place. More generally, tailoring has been reported as an indirect long-term collaboration between developers and users, suggesting the active participation of developers into this process (Mørch & Mehandjiev, 2000). At the same time, groupware systems are already known to be evolutionary because the composition and the characteristics of workgroups change with time, as well as the tasks that need to be accomplished (Fuks, et al., 2005). As was the case with the dimensions, to the best of our knowledge a scheme similar to the micro-meta-groupware for configurations has never been proposed and we believe that it can be a starting point for the incorporation of collaborative features into the design and deployment of AT systems and devices. It clarifies the complexity and challenges of designing and building AT systems. It explicitly brings into the problem space the understanding that collaboration can make significant difference in the success of an AT system.

7.3.
Multi-modal interaction

Dealing with extreme cases, like a severely impaired user, presents particular challenges that may not be present or not clear when we study a general population of users. Moreover, some aspects may play a different role, or be more or less significant to this particular group of users. One challenge that we identified concerns the need for multiple interaction modalities in order to overcome the user limitations. Dealing with severe cases, what can be a matter of convenience or comfort to a general population turns to be a success factor that enables the user to effectively accomplish some task. We experienced that when we had to implement the voice command interface in our prototype, enabling our participant to control the devices using his voice in a situation where he could not use head gestures. We believe an even better result can be achieved by mixing different modes of interaction (voice, gestures and even others). Indeed, combining more than one modality or interaction technique has already been tried as a way to improve the performance of interaction systems to users with severe motor-impairment (Biswas, et al., 2013). One interaction mode stands as a redundancy or fallback of the other, to be used when the user gets tired, temporarily unable to use one of them or even as a way to achieve a better performance in some specific task. This situations may happen due to changes in personal conditions (*e.g.*, health problems, as was the case in our second study), changes in circumstances (*e.g.*, the environment gets too noisy, interfering with the user's voice) or the nature of some desired task (*e.g.*, the voice recognition can be better suited for typing texts, but head gestures may be the preferred way for drawing figures or playing games). From the system perspective, we believe that a solution to such problem requires an approach that supports multiple interaction modalities, with the capability to interpret inputs from different modes, as we initially investigated using our prototype. Pushing this idea even further, systems must be endowed with the capability to adapt the information presentation to the abilities and skills of the user and to the context of use, characterized by the existing devices and the surrounding environment. Multimodal input interpretation (involving recognition of speech, gestures, and possibly other modalities), and distribution and adaptation of output rendering over different modalities are the focus of other work (Duarte, et al., 2013). We believe that more research is needed because it represents a promising approach to AT and accessible systems. In such systems, configuration play an even more important role, as the possibility of combinations will greatly increase.

7.4. The other “H” in HCI

Among Computer Science research fields, we chose Human-Computer Interaction as the main concentration area of this research. One of the reasons why we did that was because when the author received his engineering degree back in the 2000’s, HCI was unpopular and neglected in most of Computer Science and Engineering schools, often regarded with some prejudice by traditional computer scientists and practitioners. Some people still think (actually, some colleagues throughout the course, for example) that it is just a sub-field and not really part of Computer Science or Engineering. For this reason, we would like to discuss configuration from another often neglected perspective: its engineering and construction. It is the perspective of “the other ‘H’ in HCI” – this one being the developer – because in the traditional view the first “H” is precisely the user. It is not that we want to foster controversy in the field, but that we understand that it is useful to shed some light in the reasons why users still face trouble when interacting with computer systems, which are the challenges faced by developers when building them.

The dimensions we have proposed in Section 6.1 and the collaborative framework in Section 6.2 does not make configuration any easier to build. Actually, it makes them harder, calling the attention to the multiple facets a designer should look when trying to build a configurable AT system. From our own experience, it is much harder to build a configurable system than a fixed, static one. We had to pay attention to the connection of the parts, we had to think where to place the borders between components, we had to think about whether and how values, parameters and meanings flow between the components and how to isolate them. It is all about decoupling, applying patterns, system architectures and re-use, core concepts of the Software Engineering discipline. In the literature, theoretical and architectural support has been proposed to translate a user's input into a generic form recognizable by any Windows-based application for input device adaptation (Wang & Mankoff, 2002), and more research is needed. We searched for industry standards and development frameworks, libraries and patterns, finding almost nothing. Several levels of engineering were involved: from hardware, when we built the electronics; to software, when we structured our codes; to semiotic engineering, when we communicated the internal meanings we were creating; and back again, when we iterated over the whole system to implement a new feature. Of course our AT platform is just a prototype, and it aims to be nothing more than that. However, from the prototyping experience, we faced many challenges that any designer faces while building commercial solutions. This prototype taught us some of the good and some of the bad parts on our implementation, enough to appreciate the good engineering practices, like modularity and decoupling of responsibilities. If configurability is to be a key factor of success of AT systems, the engineering behind a configurable system seems to be another theme of paramount importance in order to support the design and implementation of better configurable AT systems. From the beginning, we were concerned with the development process of such systems because we envisage that the effective, efficient and sustainable commercial production of any technology is a key factor to promote its quality and evolution. Naturally, to propose solutions to this problem is beyond the scope of this work. For now, we acknowledge its importance, and point it as another relevant research direction to be further investigated.

7.5. Interdisciplinarity

Intrinsically, AT is an interdisciplinary and applied domain (Silva, 2011). It mixes social, medical, design and engineering knowledge areas (not in this or any other specific order) in a very singular way, in which problems tend to be solved only at the individual level. As Computer Science researchers, we probably lack the necessary knowledge to conduct research in the AT domain by ourselves. However, so does the physician, the therapist, the designer, the social scientist and probably all those who will assess this work. Despite the enormous challenges, we have to try it in order to promote the quality of life of those who need AT, who are, ultimately, at some point in life, every one of us.

Even if we consider only the Computer Science field, it was not a trivial task to join different research areas, such as EUD and Ubicomp, for example. It made it harder to frame and report, harder to find appropriate audiences, harder to publish and even harder to get constructive feedback. It greatly amplified the spectrum of literature we needed to review, evaluate and select. This work is not intended to explain the challenges of doing interdisciplinary research. However, we feel obliged to give our testimony about the difficulties of performing it, based on our very concrete research practice experience. As we said before, we thought that approaching them together could bring significant benefits, offering different perspectives from what is usually seen when each topic is researched isolated. We conducted an interdisciplinary research, mixing research areas that are usually considered apart, such as EUD, Ubicomp and AT, and also mixing perspectives that are not usually investigated together, such as user experience and development process. We consider this to be somewhat an innovative approach, or at least, an unseen one. Overall, we believe that it was worth it because we see our results as significant contributions, opening promising directions to future work.

7.6. This is about EUD

The current state of technology suggests that, in a world of ubiquitous computing, it is unlikely that a single device will be able to perform all the desired functions a user might desire or need, the same way it is unlikely that a single solution or platform will support all users' needs, the same way it is unlikely that a single brand will be able to supply a complete solution with all the desired features of what each user think is a smart environment. Moreover, dealing with a pleiade of heterogeneous devices directly might be overwhelming to most people, even the most interested and proficient in operating technology and modern gadgets. In this context, EUD may help users to take control of their solutions without having to deal directly with details of each specific device interface, or not having to depend on each manufacturer's product roadmap. Besides, combination of features among different devices makes EUD an even more powerful approach in tailoring a smart technology enhanced environment, since it opens combinatorial possibilities of tailored features through small programs that performs very specific tasks, like triggering events due to some sensor input to manage home automation, private safety systems, wellness and healthcare applications, etc. On the other side, not succeeding to provide functional and practical interoperability between the surrounding devices may compromise the possible benefit that ubiquitous computing could provide. In this work, we have investigated how EUD can be applied to deal with different, heterogeneous devices which compose our AT prototype platform. Initially, we did it because we were interested in EUD as a research and practice field. However, from the beginning we noticed that it was necessary for to us to zoom out from the programming and development aspects to a broader, contextualized view in which EUD constitutes one of the necessary techniques to be employed in order to adapt a system to some specific need. This view does not diminishes EUD; it augments it by promoting an applied and contextualized vision of its role in our current technology and information society. It brings EUD closer to Computing by reducing the distance between using a system and developing one, which can be seen as nothing more than using a specific breed of systems, namely: modeling and development tools and programming languages and environments. It brings Computing closer to Life by making it possible and comprehensible by a larger population that might not be interested in learning Computing theories, but that are immersed in a pressing need to better use technology as tool for living. Recall that, in Section 5.2.5, the only difference that the participant saw between the limitations of our “WHEN-TRIGGER-THEN-ACTION” engine and the configurations he needed to do was that, in the first case, the researcher as the developer should be the one to perform it:

> *“It has those more advanced commands that you were saying, but I also think it's a matter of configuration, that you can work in that commands and the like...”*

From the user practical point of view, there is no noticeable difference from programming and configuring besides the fact that he was provided with no means to, at least, try the first option. To make it possible, accessible and reasonable from a pragmatic user perspective should be the principal research focus of the field for which a rethinking of many core concepts of the entire Computer Science is necessary. For example, we think about open source applications when the code is made available to a developers' community. Although any user can be part of that community, there is a big distance between interfering in the system from this perspective and directly changing a system's behavior in my particular, maybe private, version of the application. And, if I do it, how do I rollback and manage my own versions of things? How do I merge them with the new community release? And how do I integrate it with other applications without having to wait for the official releases? It seems to us an interesting and attractive set of challenging and quite unexplored problems to expose to the users the bare bowels and guts of the Computer Science and Engineering field.

7.7. Conclusion

As a starting point, our research question was that *the ability for the user to adapt his or her own technology may have the potential to improve the user experience and the quality of the products of AT (and of the development of the products)*. We referred to configurations as the means by which the user adapts technology to his needs. The need for configurability, personalization, tailorability (all used here as synonyms) seems to be an essential AT feature, more than a desirable quality, but one that can substantially determinate its success. There is a general understanding that a configuration is associated with the idea of being able to define, change or choose options among a set of pre-offered possibilities. However, what and how to do it is usually not made explicit. The dimensions of end-user AT configuration we proposed in Section 6.1 are a first step towards clarifying this concept for AT designers. They offer a different perspective of the problem from other software tailoring and personalization theories, such as (Mørch, 1997); (Germonprez, et al., 2007); (Blom & Monk, 2003). Comparing to them, the dimensions zoom out because they look beyond the software, but also to the hardware design, addressing the "what" and "how" to be configured, which seems to be the remaining gaps in this topic. We showed how these dimensions help to analyze and to identify the techniques, technologies and approaches that may suit each configuration need of an AT system under design. To the best of our knowledge, this characterization of the problem space has never been proposed and we conclude that it is somehow innovative. This also means it is probably neither a complete nor an exhaustive set: for example, there may exist other dimensions regarding context, place and purpose that can be useful in guiding the design from complementary perspectives. Therefore it should be further investigated in future work, so it can be confirmed, improved and refined, as well as compared and linked with other related frameworks, models and theories.

Additionally, we sought to investigate how we could build AT infrastructure based on smart devices and smart environments using the currently available IoT technology. Our prototype showed that it is technologically and economically feasible, at least in the small scale. Last century was the time when sophisticated miniaturized electronics were luxury goods restricted to large high tech corporations, military projects or the extremely wealthy. We are neither hardware (electronics) nor (product) design experts, and still we built a working prototype within limited time and budget resources. Our testimony must constitute a stimulus for researchers and practitioners who want to engage in similar endeavors. Moreover, it may constitute the assertion of a proper condition for the proliferation of the DIY and personal fabrication culture. As we mentioned in Section 3, DIY-AT has already been proposed by some researchers, as an answer to high AT product costs, limitations, challenges (personalization being one of them) and abandonment issues. Our work should reinforce that it is feasible and constitutes a promising approach, at least from the technologically perspective.

Moreover, we wanted to investigate the frontiers of EUD, exploring the aspects of ubiquity, multiple end-users and “development” not only as software development, but from a broader concept of technology construction. The configuration dimensions and the micro-meta-groupware we proposed here are initial steps towards what we believe is a much broader territory for investigating and applying EUD. Many other researchers from different research areas are interested in one or another aspect of it, one of the reasons Section 3.2 (the intersection between EUD and Ubicomp) was the most voluminous in bibliographic references, and it is not even close to be a complete literature review on the topic. Like the others, we believe that we are just “scratching the surface” of what can be a much vaster territory to the Computer Science field, in which programming is seen and performed as "an opportunistic, physically active, and playful activity, situated within the very same physical context as the pervasive systems being built" (Elumeze, 2010). As Elumeze had already envisioned, ambient programming must embrace not only a single system, but an ecosystem of equals and different devices. We complement this vision, stating that this kind of programming will also be immersed into a collaborative and applied practical activity, which is precisely that of building the personally relevant technology we need. It is not only about software, but about the tools we need to live with, which include the hardware and the physical environment; it is not only about programming, but about building upon other people previous work, as always is the case, not mattering if it is a "finished" software with parameters to be set or a programming language and environment to code, a "finished" house with some empty spaces to fill in or brick, cement and mortar to build it from scratch; it is not only about myself, but always about myself and somebody else who built something before me which I use, being it a software or a house, a programming language or a brick.

Bibliography

ABAWAJY, J. H. **Human-computer interaction in ubiquitous computing environments**. International journal of pervasive computing and communications, v. 5, n. 1, p. 61-77, 2009.

ALAM, M. R.; REAZ, M. B. I.; ALI, M. A. M. **A review of smart homes—Past, present, and future**. Systems, Man, and Cybernetics, Part C: Applications and Reviews, IEEE Transactions on, v. 42, n. 6, p. 1190-1203, 2012.

ALEMDAR, H.; ERSOY, C. **Wireless sensor networks for healthcare**: A survey. Computer Networks, v. 54, n. 15, p. 2688-2710, 2010.

ANDERSON, C. **Makers: the new industrial revolution**. 2012. New York: Crown Business.

ANDERSON, G.; HERR, K. **The action research dissertation: A guide for students and faculty**. Sage, 2014.

ASHTON, K. **That 'internet of things' thing**. RFiD Journal, v. 22, n. 7, p. 97-114, 2009.

ATZORI, L.; IERA, A.; MORABITO, G. **The internet of things: A survey**. Computer Networks, v. 54, n. 15, p. 2787-2805, 2010.

BARBOSA, S. D. J.; DA SILVA, B. S. **Interação Humano-Computador**. Elsevier-Campus, 2010.

BARRICELLI, B. R.; VALTOLINA, S. **Designing for End-User Development in the Internet of Things**. In: End-User Development, IS-EUD 2015, Proceedings. Springer, 2015. p. 9-24,

BIGHAM, J. P.; BRUDVIK, J. T.; ZHANG, B. **Accessibility by demonstration: enabling end users to guide developers to web accessibility solutions**. In: Proceedings of the 12th international ACM SIGACCESS conference on Computers and accessibility (ASSETS '10). ACM, 2010. p. 35-42.

BIGHAM, J. P.; LADNER, R. E. **Accessmonkey: a collaborative scripting framework for web users and developers**. In: Proceedings of the 2007 international cross-disciplinary conference on Web accessibility (W4A) (W4A '07). ACM, 2007. p. 25-34.

BISWAS, P. et al. **Interaction techniques for users with severe motor-impairment**. In: A Multimodal End-2-End Approach to Accessible Computing. London: Springer, 2013. p. 119-134.

BLACKWELL, A. F. **End-user developers at home**. Communications of the ACM, v. 47, n. 9, p. 65-66, 2004.

BLACKWELL, A. F.; HAGUE, R. AutoHAN: **An architecture for programming the home**. In: Human-Centric Computing Languages and Environments, 2001. Proceedings IEEE Symposia on. IEEE, 2001-a. p. 150-157.

BLACKWELL, A. F.; HAGUE, R., **Designing a programming language for home automation**. In: Proceedings of the 13th Annual Workshop of the Psychology of Programming Interest Group (PPIG 2001). 2001-b. p. 85-103.

BLOM, J. O.; MONK, A. F. **Theory of Personalization of Appearance: Why Users Personalize Their PCs and Mobile Phones**. Human-Computer Interaction, v. 18, n. 3, p. 193-228, 2003.

BOOTH, T.; STUMPF, S. **End-user experiences of visual and textual programming environments for Arduino**. In: End-User Development, IS-EUD 2013, Proceedings. Springer, 2013. p. 25-39.

BORGES, J. A. **Projeto Motrix - NCE/UFRJ**. 2002. Available at: <http://intervox.nce.ufrj.br/motrix/>. Accessed on: 10 August 2015.

BRANDÃO, R.; DE SOUZA, C.; CERQUEIRA, R. **Uma infraestrutura de captura & acesso para instrumentação de avaliações qualitativas de IHC**. In: Proceedings of the 13th Brazilian Symposium on Human Factors in Computing Systems. Sociedade Brasileira de Computação, 2014. p. 197-206.

BRASIL. **Decreto Nº 3.298, de 20 de dezembro de 1999**. Provides for the National Policy for the Integration of Persons with Disabilities, consolidates protection regulations, and other measures. 1999. Available at:

<http://www.planalto.gov.br/ccivil_03/decreto/d3298.htm>. Accessed on: 29 May 2014.

BRASIL. **Decreto Nº 7.612, de 17 de novembro de 2011**. Establishes the National Plan for the Rights of Persons with Disabilities - Plano Viver Sem Limites. 2011. Available at: <http://www.planalto.gov.br/ccivil_03/_Ato2011-2014/2011/Decreto/D7612.htm>. Accessed on: 30 July 2014.

BRASIL. Subsecretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência. Comitê de Ajudas Técnicas. **Tecnologia Assistiva**. Brasília: CORDE, 2009. 138 p.

Carmien, S. et al. **Socio-technical environments supporting people with cognitive disabilities using public transportation**. ACM Transactions on Computer-Human Interaction (TOCHI), v. 12, n. 2, p. 233-262, 2005.

CARMIEN, S. P.; FISCHER, G. **Design, adoption, and assessment of a socio-technical environment supporting independence for persons with cognitive disabilities**. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM, 2008. p. 597-606.

CARRINGTON, P.; HURST, A.; KANE, S. K. **Wearables and chairables: inclusive design of mobile input and output techniques for power wheelchair users**. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM, 2014. p. 3103-3112.

CHAGAS, B. A.; FUKS, H.; DE SOUZA, C. S. **Lessons Learned in the Design of Configurable Assistive Technology with Smart Devices**. In: End-User Development, IS-EUD 2015, Proceedings. Springer, 2015-a. p. 180-185.

CHAGAS, B. A.; FUKS, H.; DE SOUZA, C. S. **Towards micro-groupware: Supporting small group activities around assistive technology**. In: IS-EUD 2015 Workshop on Cultures of Participation in the Digital Age (CoPDA 2015). Springer, 2015-b (in press).

CHAN, M. et al. **Smart homes—current features and future perspectives**. Maturitas, v. 64, n. 2, p. 90-97, 2009.

CHAN, M. et al. **A review of smart homes—Present state and future challenges**. Computer methods and programs in biomedicine, v. 91, n. 1, p. 55-81, 2008.

CHAN, M. et al. **Smart wearable systems: Current status and future challenges**. Artificial intelligence in medicine, v. 56, n. 3, p. 137-156, 2012.

CHOI, Y. S. et al. **Laser pointers and a touch screen: intuitive interfaces for autonomous mobile manipulation for the motor impaired**. In: Proceedings of the 10th international ACM SIGACCESS conference on Computers and accessibility. ACM, 2008. p. 225-232.

COLE, E.; DEHDASHTI, P. **Patient-centered design as a research strategy for cognitive prosthetics: Lessons learned from working with patients and clinicians for 2 decades**. In: CHI 2006 Workshop on Designing Technology for People with Cognitive Impairments. 2006.

CUCCURULLO, S. et al. **MicroApps Development on Mobile Phones**. In: End-User Development, IS-EUD 2011, Proceedings. Springer, 2011. p. 289-294.

CYPHER, A.; HALBERT, D. C. **Watch what I do: programming by demonstration**. MIT press, 1993.

DAVIDOFF, S. et al. **Principles of smart home control**. In: UbiComp 2006: Ubiquitous Computing. Springer, 2006. p. 19-34.

DAVISON, F. **QuadStick - A game controller for quadriplegics**. 2014. Available at: <http://www.quadstick.com/>. Accessed on: 08 August 2015.

DAX, J. et al. **FRAMES – A Framework for Adaptable Mobile Event-Contingent Self-report Studies**. In: End-User Development, IS-EUD 2015, Proceedings. Springer, 2015. p. 141-155.

DE SOUZA, C. S.; BARBOSA, S. D. J. **A semiotic framing for end-user development**. In: End User Development. Springer, 2006. p. 401-426.

DOLLAR, A. M.; HERR, H. **Lower extremity exoskeletons and active orthoses: challenges and state-of-the-art**. Robotics, IEEE Transactions on, v. 24, n. 1, p. 144-158, 2008.

DOURISH, P. **Where the action is: the foundations of embodied interaction**. MIT press, 2004.

DUARTE, Carlos et al. **Building an Adaptive Multimodal Framework for Resource Constrained Systems**. In: A Multimodal End-2-End Approach to Accessible Computing. Springer, 2013. p. 155-173.

EISENBERG, M. et al. **Children's programming, reconsidered: settings, stuff, and surfaces**. In: Proceedings of the 8th International Conference on Interaction Design and Children. ACM, 2009. p. 1-8.

ELUMEZE, N. O. **Ambient programming**. 2010. 147p. Ph.D. Thesis - University of Colorado at Boulder. Advisor: Michael Eisenberg.

EYSENBACH, G. **Medicine 2.0: social networking, collaboration, participation, apomediation, and openness**. Journal of medical Internet research, v. 10, n. 3, 2008. Avalibale at: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2626430/>.

FILIPPO, D. D. R. **Suporte à coordenação em sistemas colaborativos: uma pesquisa-ação com aprendizes e mediadores atuando em fóruns de discussão de um curso a distância**. Rio de Janeiro, 2008. 281p. D.Sc. Thesis - Pontifícia Universidade Católica do Rio de Janeiro. Advisor: Hugo Fuks.

FISCHER, G. **Understanding, fostering, and supporting cultures of participation**. Interactions, v. 18, n. 3, p. 42-53, 2011.

FISCHER, G.; GIACCARDI, E. **Meta-design: A framework for the future of end-user development**. In: End user development. Springer, 2006. p. 427-457.

FISCHER, G. et al. **Meta-design: a manifesto for end-user development**. Communications of the ACM, v. 47, n. 9, p. 33-37, 2004.

FOTH, M.; AXUP, J. **Participatory Design and Action Research: Identical Twins or Synergetic Pair?** In: Proceedings Participatory Design Conference 2006: Expanding Boundaries in Design 2 (Trento, Italy). 2006. p. 93-96.

FUKS, H. et al. **Applying the 3C model to groupware development**. International Journal of Cooperative Information Systems, v. 14, n. 02n03, p. 299-328, 2005.

GALVÃO FILHO, T. A. **A Tecnologia Assistiva: de que se trata?** In: MACHADO, G. J. C.; SOBRAL, M. N. (Orgs.). Conexões: educação, comunicação, inclusão e interculturalidade. 1 ed. Porto Alegre: Redes Editora, p. 207-235, 2009.

GERMONPREZ, M.; HOVORKA, D.; COLLOPY, F. **A theory of tailorable technology design**. Journal of the Association for Information Systems, v. 8, n. 6, p. 21, 2007.

GEROSA, M. A. et al. **Is the unfolding of the group discussion off-pattern? Improving coordination support in educational forums using mobile devices**. Computers & Education, v. 54, n. 2, p. 528-544, 2010.

GLINERT, E. P.; YORK, B. W. **Computers and people with disabilities**. ACM Transactions on Accessible Computing (TACCESS), v. 1, n. 2, p. 7, 2008.

HAGUE, R.; BLACKWELL, A. F.; ROBINSON, P. **End-User Programming in the Networked Home**. In: Proceedings of the 1st Equator Workshop on Ubiquitous Computing in Domestic Environments. 2001. p. 46-67.

HATCH, M. **The Maker Movement Manifesto: Rules for Innovation in the New World of Crafters, Hackers, and Tinkerers**. McGraw-Hill, 2013.

HURST, A.; KANE, S. **Making making accessible**. In: Proceedings of the 12th International Conference on Interaction Design and Children. ACM, 2013. p. 635-638.

HURST, A.; TOBIAS, J. **Empowering individuals with do-it-yourself assistive technology**. In: The proceedings of the 13th international ACM SIGACCESS conference on Computers and accessibility. ACM, 2011. p. 11-18.

HWANG, A.; TRUONG, K. N.; MIHAILIDIS, A. **Using participatory design to determine the needs of informal caregivers for smart home user interfaces**. In: Pervasive Computing Technologies for Healthcare (PervasiveHealth), 2012 6th International Conference on. IEEE, 2012. p. 41-48.

IBGE - Instituto Brasileiro de Geografia e Estatística. **Censo Demográfico 2010: Características gerais da população, religião e pessoas com deficiência**. 2010. Available at:
<http://www.ibge.gov.br/home/estatistica/populacao/censo2010/caracteristicas_re

ligiao_deficiencia/default_caracteristicas_religiao_deficiencia.shtm>. Accessed on: 27 May 2014.

ISHII, H.; ULLMER, B. **Tangible bits: towards seamless interfaces between people, bits and atoms**. In: Proceedings of the ACM SIGCHI Conference on Human factors in computing systems. ACM, 1997. p. 234-241.

ITU - International Telecommunication Union. **ITU Internet Reports - The Internet of Things**. 2005. Available at: <http://www.itu.int/wsis/tunis/newsroom/stats/The-Internet-of-Things-2005.pdf>. Accessed on: 16 July 2014.

KANE, S. K. et al. **Freedom to roam: a study of mobile device adoption and accessibility for people with visual and motor disabilities**. In: Proceedings of the 11th international ACM SIGACCESS conference on Computers and accessibility. ACM, 2009. p. 115-122.

KINTSCH, A.; DEPAULA, R. **A framework for the adoption of assistive technology**. In: Proceedings of the SWAAAC 2002: Supporting learning through assistive technology. 2002. p. 1-10.

KOCK JR, N. F.; MCQUEEN, R. J.; JOHN, L. S. **Can action research be made more rigorous in a positivist sense? The contribution of an iterative approach**. Journal of Systems and Information Technology, v. 1, n. 1, p. 1-23, 1997.

KOCK, N. **Action research: its nature and relationship to human-computer interaction**. In: SOEGAARD, M.; DAN, R. F. (Eds). The Encyclopedia of Human-Computer Interaction, 2nd Ed., 2013. Available at: <https://www.interaction-design.org/literature/book/the-encyclopedia-of-human-computer-interaction-2nd-ed/action-research-its-nature-and-relationship-to-human-computer-interaction>.

KOPETZ, H. **Internet of things**. In: Real-time systems. Springer, 2011. p. 307-323.

KUBITZA, T.; SCHMIDT, A. **Towards a Toolkit for the Rapid Creation of Smart Environments**. In: End-User Development, IS-EUD 2015, Proceedings. Springer, 2015. p. 230-235.

LADNER, R. E. **Access and empowerment: Commentary on "Computers and people with disabilities"**. ACM Transactions on Accessible Computing (TACCESS), v. 1, n. 2, p. 11, 2008.

LAZAR, J.; FENG, J. H.; HOCHHEISER, H. **Research methods in human-computer interaction**. John Wiley & Sons, 2010.

LEBEDEV, M. A. et al. **Future developments in brain-machine interface research**. Clinics, v. 66, p. 25-32, 2011.

LEWIS, C. **Simplicity in cognitive assistive technology: a framework and agenda for research**. Universal Access in the Information Society, v. 5, n. 4, p. 351-361, 2007.

LIEBERMAN, H. et al. **End-user development: An emerging paradigm**. Springer, 2006.

LIGHT, A. **Adding method to meaning: a technique for exploring peoples' experience with technology**. Behaviour & Information Technology, v. 25, n. 2, p. 175-187, 2006.

LINDTNER, S.; HERTZ, G. D.; DOURISH, P. **Emerging sites of HCI innovation: hackerspaces, hardware startups & incubators**. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM, 2014. p. 439-448.

LIN, H. W.; AFLATOONY, L.; WAKKARY, R. **Design for one: a game controller for a quadriplegic gamer**. In: CHI'14 Extended Abstracts on Human Factors in Computing Systems. ACM, 2014. p. 1243-1248.

LUCCI, G.; PATERNÒ, F. **Understanding end-user development of context-dependent applications in smartphones**. In: Human-Centered Software Engineering. Springer, 2014. p. 182-198.

MALU, M.; FINDLATER, L. **Personalized, Wearable Control of a Head-mounted Display for Users with Upper Body Motor Impairments**. In: Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems. ACM, 2015. p. 221-230.

MAUÉS, R. d. A.; BARBOSA, S. D. J. **Keep doing what I just did: automating smartphones by demonstration**. In: Proceedings of the 15th international conference on Human-computer interaction with mobile devices and services. ACM, 2013. p. 295-303.

MIHAILIDIS, A. et al. **The COACH prompting system to assist older adults with dementia through handwashing: An efficacy study**. BMC geriatrics, v. 8, n. 1, p. 28, 2008.

MILLNER, A.; BAAFI, E. **Modkit: blending and extending approachable platforms for creating computer programs and interactive objects**. In: Proceedings of the 10th International Conference on Interaction Design and Children. ACM, 2011. p. 250-253.

MORAITI, A. et al. **Empowering Occupational Therapists with a DIY-toolkit for Smart Soft Objects**. In: Proceedings of the Ninth International Conference on Tangible, Embedded, and Embodied Interaction. ACM, 2015. p. 387-394.

MØRCH, A. **Three levels of end-user tailoring: Customization, integration, and extension**. In: KYNG, M.; MATHIASSEN, L. (Eds). Computers and design in context. MIT, 1997. p. 51-76.

MØRCH, A. I.; MEHANDJIEV, N. D. **Tailoring as collaboration: The mediating role of multiple representations and application units**. Computer Supported Cooperative Work (CSCW), v. 9, n. 1, p. 75-100, 2000.

MOTA, C. **The rise of personal fabrication**. In: Proceedings of the 8th ACM conference on Creativity and cognition. ACM, 2011. p. 279-288.

MULLER, M. J.; KUHN, S. **Participatory design**. Communications of the ACM, v. 36, n. 6, p. 24-28, 1993.

NARDI, B. A. **A small matter of programming: perspectives on end user computing**. MIT press, 1993.

NEVES, V. F. A. **Pesquisa–ação e etnografia: caminhos cruzados**. Revista de práticas psicossociais, v. 1, n. 1, 2006.

NEWMAN, M. W. et al. **Designing for serendipity: supporting end-user configuration of ubiquitous computing environments**. In: Proceedings of the 4th conference on Designing interactive systems: processes, practices, methods, and techniques. ACM, 2002. p. 147-156.

NGUYEN, H. et al. **El-e: An assistive robot that fetches objects from flat surfaces**. In: Robotic helpers, int. conf. on human-robot interaction. 2008.

OLIVEIRA, Luiza M. B. **Cartilha do Censo 2010 – Pessoas com deficiência**. Brasília: Secretaria de Direitos Humanos da Presidência da República (SDH/PR), Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência (SNPD), Coordenação-Geral do Sistema de Informações sobre a Pessoa com Deficiência, 2012. Available at: <http://www.sdh.gov.br/assuntos/pessoa-com-deficiencia/dados-estatisticos/pesquisas-demograficas>. Accessed on: 29 May 2014.

O'DAY, B.; KILLEEN, M. **Research on the Lives of Persons with Disabilities - The Emerging Importance of Qualitative Research Methodologies**. Journal of Disability Policy Studies, v. 13, n. 1, p. 9-15, 2002.

PERERA, C.; AGHAEE, S.; BLACKWELL, A. **Natural Notation for the Domestic Internet of Things**. In: End-User Development, IS-EUD 2015, Proceedings. Springer, 2015. p. 25-41.

PIMENTEL, M.; FUKS, H. **Sistemas Colaborativos**. Elsevier, 2011.

ROSS, D. et al. **Implementing assistive technology on wearable computers**. Intelligent Systems, IEEE, v. 16, n. 3, p. 47-53, 2001.

SCHWEIKARDT, E.; GROSS, M. D. **A brief survey of distributed computational toys**. In: Digital Game and Intelligent Toy Enhanced Learning, 2007. DIGITEL'07. The First IEEE International Workshop on. IEEE, 2007. p. 57-64.

SILVA, L. C. d. **O design de equipamentos de tecnologia assistiva como auxílio no desempenho das atividades de vida diária de idosos e pessoas como deficiência, socialmente institucionalizados.** 2011. Masters Dissertation - Universidade Federal do Rio Grande do Sul. Advisor: Vilson Joao Batista.

STEFANOV, D. H.; BIEN, Z.; BANG, W.-C. **The smart house for older persons and persons with physical disabilities: structure, technology arrangements, and perspectives**. Neural Systems and Rehabilitation Engineering, IEEE Transactions on, v. 12, n. 2, p. 228-250, 2004.

SUSMAN, G. I.; EVERED, R. D. **An assessment of the scientific merits of action research**. Administrative science quarterly, p. 582-603, 1978.

TETTEROO, D.; MARKOPOULOS, P. **A Review of Research Methods in End User Development**. In: End-User Development, IS-EUD 2015, Proceedings. Springer, 2015. p. 58-75.

United Nations in Brazil. **A ONU e as pessoas com deficiência**. Available at: <http://nacoesunidas.org/acao/pessoas-com-deficiencia/>. Accessed on: 19 July 2015.

UNITED STATES (105th Congress). **Assistive Technology Act of 1998, S. 2432**. 1998. Available at: <http://www.section508.gov/assistive-technology-act-1998>. Accessed on: 17 Dec. 2014.

UR, B. et al. **Practical trigger-action programming in the smart home**. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM, 2014. p. 803-812.

VANDERHEIDEN, G. C. **Redefining assistive technology, accessibility and disability based on recent technical advances**. Journal of Technology in Human Services, v. 25, n. 1-2, p. 147-158, 2007.

VANDERHEIDEN, G. C. **Ubiquitous accessibility, common technology core, and micro assistive technology: Commentary on "computers and people with disabilities"**. ACM Transactions on Accessible Computing (TACCESS), v. 1, n. 2, p. 10, 2008.

VANDERHEIDEN, G. C.; JORDAN, J. B. **Design for people with functional limitations**. In: Handbook of Human Factors and Ergonomics, Fourth Edition. Wiley, 2006. p. 1407-1441.

VEGA, K.; FUKS, H. **Beauty technology as an interactive computing platform**. In: Proceedings of the 2013 ACM international conference on Interactive tabletops and surfaces. ACM, 2013. p. 357-360.

WANG, J.; MANKOFF, J. **Theoretical and architectural support for input device adaptation**. In: Proceedings of the 2003 conference on Universal usability (CUU '03). ACM, 2002. p. 85-92.

WEISER, M. **The computer for the 21st century**. Scientific american, v. 265, n. 3, p. 94-104, 1991.

WEISER, M. **Some computer science issues in ubiquitous computing**. Communications of the ACM, v. 36, n. 7, p. 75-84, 1993.

World Health Organization. **Disability and health - Fact sheet No. 352**. 2014 Available at: <http://www.who.int/mediacentre/factsheets/fs352/en/>. Accessed on: 24 August 2015.

WRIGHT, P.; MCCARTHY, J. **Empathy and experience in HCI**. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM, 2008. p. 637-646.

Annex I – Research protocol (in Portuguese)

PONTIFÍCIA UNIVERSIDADE CATÓLICA DO RIO DE JANEIRO
DEPARTAMENTO DE INFORMÁTICA
SETEMBRO/2014

Projeto de Pesquisa

End-User Development e Internet das Coisas Aplicados à Tecnologia Assistiva

Proposta de Dissertação de Mestrado

Pesquisador: Bruno Azevedo Chagas – candidato ao título de Mestre em Ciências em Informática pelo Departamento de Informática da Pontifícia Universidade Católica do Rio de Janeiro
http://lattes.cnpq.br/9225583130377872

Contato: *bchagas@inf.puc-rio.br*

Orientadores: Profs. Hugo Fuks (*hugo@inf.puc-rio.br*) e Clarisse Sieckenius de Souza (*clarisse@inf.puc-rio.br*)

Endereço: Rua Marquês de São Vicente, 225, Gávea - Rio de Janeiro

PONTIFÍCIA UNIVERSIDADE CATÓLICA DO RIO DE JANEIRO
DEPARTAMENTO DE INFORMÁTICA

SETEMBRO/2014

Sumário

1 Introdução

Este documento apresenta os objetivos e descrição de linhas gerais para projeto de pesquisa a ser realizado como tema de dissertação de mestrado em Informática no DI na área de concentração de Interação Humano-Computador (IHC), buscando unir as linhas de pesquisa de *End-User Development* e Internet das Coisas para desenvolver avanços científicos e tecnológicos no domínio da Tecnologia Assistiva.

2 Contextualização

A seguir apresentamos as linhas de pesquisa que formam os pilares do trabalho a ser feito.

2.1 End-User Development

Uma abordagem para o desenvolvimento de sistemas computacionais úteis e agradáveis de se usar é dizer que os projetistas precisam de melhores metodologias e ferramentas para compreender os usuários e seus contextos, e para codificar esse entendimento em softwares fechados. Outra é reconhecer que sempre haverá necessidades não atendidas dos usuários, e que o caminho para aumentar a satisfação dos usuários é ajudá-los a modificar os sistemas, a fim de atender às exigências de constantes mudanças (de Souza & Barbosa, 2006).

End-User Development[1] (*EUD*, i.e., *"desenvolvimento de software pelo usuário final"*) refere-se a um conjunto de métodos, técnicas e ferramentas que permitem aos usuários finais de sistemas computacionais atuarem como desenvolvedores de software não-profissionais para criar, modificar ou estender software. Tais métodos, técnicas e ferramentas oferecem aos usuários a possibilidade de configurar, adaptar e evoluir os sistemas por si mesmos e em tempo de uso (Lieberman, et al., 2006).

Num mundo onde a tecnologia evolui rapidamente e os lugares, objetos e as coisas ao nosso redor se tornam dotados de comportamento através de *software*, tal questão ganha importância humana, social e econômica, pois endereça diretamente a capacidade das pessoas de atuar e controlar o mundo ao seu redor.

2.2 Internet das Coisas

A Internet das Coisas (em inglês, *Internet of Things* – IoT) é um novo paradigma cuja ideia básica é a presença generalizada ao nosso redor de uma variedade de *coisas* – objetos identificados, sensores, atuadores, computadores, telefones celulares, etc. – que, através de

[1] Devido à extensão da expressão em português que traduz corretamente o sentido do termo em inglês, usaremos o termo e o acrônimo originais em inglês para agilizar a leitura.

comunicação sem fio e um esquema de identificação única, são capazes de interagir umas com as outras e cooperar com seus vizinhos para alcançar objetivos comuns (Atzori, et al., 2010). O termo "Internet das Coisas" é atribuído originalmente a (Auto-ID Labs, s.d.), com o foco inicial no desenvolvimento de códigos eletrônicos de identificação universal de produtos para apoiar o uso generalizado de RFID (*Radio-Frequency IDentification*) em redes comerciais. Hoje, as visões da Internet das coisas abrangem um conceito muito mais amplo, e múltiplas definições e facetas da Internet das Coisas são descritas na comunidade científica. Isto atesta o forte interesse sobre o tema, que engloba uma grande variedade de tecnologias, domínios e aplicações, bem como questões éticas e sociais, como segurança e privacidade, que formam extenso campo de tópicos de pesquisa, muitos ainda sob investigação (Atzori, et al., 2010).

A conexão das *coisas físicas* com a Internet faz com que seja possível acessar dados de sensores remotos e controlar o mundo físico à distância, onde *objetos inteligentes* formam os blocos de construção de uma nova realidade de computação ubíqua (Kopetz, 2011, p. 307). Pelo potencial de inovação, a Internet das Coisas atrai também o interesse da indústria, principalmente (mas não somente) dos setores de tecnologia e telecomunicações:

"The next step in this technological revolution is to connect inanimate objects and things to communication networks. This is the vision of a truly ubiquitous network – 'anytime, anywhere, by anyone and anything' " (ITU - International Telecommunication Union, 2005).

As possibilidades são inúmeras e muitos acreditam ser uma *nova revolução tecnológica:*

"A Internet das coisas é uma revolução tecnológica que representa o futuro da computação e da comunicação e cujo desenvolvimento depende da inovação técnica dinâmica em campos tão importantes como os sensores wireless e a nanotecnologia." (Wikipedia - Português, 2014)

Previsões a parte, há potencial real para significativas transformações sociais, motivo pelo qual o tema tem atraído a atenção de pesquisadores, empresas e governos em todo o mundo, inclusive sendo objeto de políticas públicas para o desenvolvimento econômico e social em nosso país (BNDES - Banco Nacional do Desenvolvimento, 2014).

O potencial vai desde infraestrutura para cidades inteligentes, automação residencial, comercial e industrial, novos produtos, serviços e ambientes interativos, entretenimento e arte digital até aplicações na área de saúde, cuidados domésticos e atendimento domiciliar. Neste último sentido, há um espaço muito grande para uma nova classe de tecnologias e aplicações na vida de pessoas com necessidades especiais.

2.3 Tecnologia Assistiva

Cerca de 10% da população mundial, aproximadamente 650 milhões de pessoas, vivem com uma deficiência. São a maior minoria do mundo, e cerca de 80% dessas pessoas vivem em países em desenvolvimento. Entre as pessoas mais pobres do mundo, 20% têm algum tipo de deficiência (ONU - Organização das Nações Unidas, s.d.). Dados do último Censo em nosso país (2010) indicam que quase 24% da população brasileira possui algum tipo de deficiência, o que é aproximadamente 45,6 milhões de brasileiros. Destes, cerca de 8,3% apresentam deficiência severa, seja visual, auditiva, motora ou intelectual/mental, o que representa aproximadamente 15,7 milhões de pessoas (Secretaria de Direitos Humanos da Presidência da República (SDH/PR) / Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência (SNPD), 2012), (IBGE - Instituto Brasileiro de Geografia e Estatística, 2010). Gradualmente, a sociedade ampliou o olhar sobre a deficiência e o seu portador para além do aspecto médico (tratamento e cura), voltando-se também para uma questão de inclusão social mais profunda e abrangente, que passa pela garantia dos direitos humanos até a participação ativa e integral dos indivíduos portadores de deficiência na sociedade.

Além disso, é um tema cuja abrangência vai bem além dos números aqui apresentados: limitações funcionais de diversas naturezas afetam a todos, em diferentes graus e momentos de suas vidas. Seja pelo envelhecimento ou mesmo sob circunstâncias cotidianas, todos estamos sujeitos a experimentarmos limitações funcionais quando: temos a locomoção comprometida devido a perna quebrada em um acidente (motora), temos os movimentos dos membros superiores comprometidos pois nossas mãos e braços estão ocupados segurando um bebê ou várias sacolas de compras (motora), o barulho da rua em um local movimentado prejudica a nossa audição (auditiva), situações de stress intenso limitam nossa capacidade de avaliação da realidade a nossa volta (mental/intelectual).

Dito isto, a questão da deficiência pode ser olhada sob a seguinte ótica:

"Disability is the inability to accommodate to the world as it is currently designed."
(Vanderheiden, 2012, p. 1410)

Esta definição chama a atenção para a relação entre deficiência e *design*, bem como para a possibilidade de ambos serem modificados, sobre o quê há três possíveis abordagens:

- *Mudar a pessoa, através de tratamentos médicos, cirurgias, implantes e até educação e treinamentos especiais;*
- *Equipar a pessoa e/ou as coisas, com ferramentas que permitam o acesso e uso por um usuário "especial" das coisas na forma como se apresentam no mundo atual;*
- *Mudar o mundo atual, através do design de lugares, produtos e serviços mais acessíveis e universais.*

Tomaremos, neste trabalho, a ênfase na segunda abordagem, usando o termo Tecnologia Assistiva (TA) para designar o conjunto de ferramentas especializadas que possam adaptar partes do mundo ao redor (produtos, objetos, serviços ou lugares) ao uso e às habilidades específicas de indivíduos com limitações funcionais. No Brasil, os termos "Tecnologia Assistiva", "Ajudas Técnicas" e "Tecnologias de Apoio" são comumente utilizados como sinônimos (Galvão Filho, 2009), sendo definido na legislação brasileira a expressão "Ajudas Técnicas" no Decreto 3298/1999, artigo 19, como:

"Os elementos que permitem compensar uma ou mais limitações funcionais motoras, sensoriais ou mentais da pessoa portadora de deficiência, com o objetivo de superar as barreiras de comunicação e da mobilidade e de possibilitar sua plena inclusão social." (BRASIL - Presidência da República, 1999)

2.4 Este Trabalho

Neste trabalho, buscamos unir as linhas de pesquisa do *End-User Development* e Internet das Coisas para desenvolver avanços científicos e tecnológicos no domínio da Tecnologia Assistiva. De fato, as tecnologias relacionadas já disponíveis hoje viabilizam o acesso a aparelhos, objetos e serviços existentes através de novos mecanismos de interação e comunicação:

"As we move toward having environments where the products can all be controlled remotely (because it is convenient for everyone), and as we move to the situation where everyone pulls out a natural language enabled cell phone or PDA to have the devices in their environment operated, we begin to have a situation where individuals with disabilities are able to use the same devices, using these same "user friendly" interfaces, as everyone else." (Vanderheiden, 2007)

Além dos impactos óbvios sobre a vida das pessoas portadoras de deficiência, há motivações científicas, econômicas e sociais mais abrangentes, pois este tipo de pesquisa relacionando tecnologia e deficiência promove o desenvolvimento científico e tecnológico, especialmente na Ciência da Computação, além de levar a inovações que são benéficas para todos os usuários, incluindo aqueles que não são portadores de deficiência (Glinert & York, 1992/2008).

Porém, os desafios envolvidos ao se tentar endereçar as especificidades de cada deficiência e seus portadores são grandes, pois existe grande variabilidade de tipos e níveis de limitações (um *continuum* entre "alguma dificuldade" e "não consegue de modo algum"), causas (genéticas, acidentes, envelhecimento) e características pessoais (físicas, como altura e peso, as suas condições sociais, psicológicas, etc.). Isso tem implicações que precisam ser consideradas e é onde a área da IHC pode trazer contribuições com suas teorias, métodos e tecnologias para projeto, avaliação e implementação de sistemas interativos, bem como para o estudo dos fenômenos ao redor deles.

Ladner (2008) nos aponta:

"A key concept that has emerged in the past ten to fifteen years is that of user centered design, where computer interface design is optimized around what the users can and want to do rather than forcing users adapt themselves to the interface. For persons with disabilities this means involving them in the design process from beginning to end. Augmenting this concept is one that I believe is equally important for this group, namely, design for user empowerment. This means designing tools that help empower persons with disabilities to create and/or configure accessibility products on their own. Since they are the most motivated to improve their lives using technology, if the mechanisms exist to empower them to do it on their own, they will."

E com isso notamos o potencial que o *End-User Development* tem em semelhante contexto, motivando um estudo de seus métodos e tecnologias aplicados a usuários portadores de deficiência para promover ou melhorar o acesso e uso das coisas ao seu redor, bem como o estudo das implicações – tecnológicas, sociais e humanas – envolvidas em semelhante esforço.

3 Parceiro de Pesquisa

As circunstâncias nos conduziram até um cenário real bem particular: um aluno da pós-graduação do IAG – Escola de Negócios da PUC-Rio – toma conhecimento da "Beauty Technology" – uma das inovações tecnológicas em interfaces desenvolvidas no DI (Vega & Fuks, 2013) – e procura os autores para conversar sobre a possibilidade de usar a mesma tecnologia para melhorar suas condições de vida. O interessado tem 33 anos, é portador de tetraplegia causada por acidente sofrido há mais de 10 anos, e não tem os movimentos abaixo da linha dos ombros. Ainda assim, ele tem uma vida muito ativa: já após o acidente graduou-se em Administração de Empresas e atualmente faz curso de mestrado na mesma área. Sua demanda nos direcionou para a realização de um trabalho específico sobre o seu contexto e cenário real de vida, envolvendo as tecnologias aqui apresentadas e tendo-o como *Usuário Principal*[2] das mesmas, que pode introduzir significativas melhorias em suas condições de autonomia e de interação com o mundo ao seu redor.

Do ponto de vista humano, nada melhor do que realizar um trabalho cujo resultado tem impacto positivo tão claro e imediato na vida de outra pessoa. Do ponto de vista científico, seu caso é um cenário real de limitação funcional que nos permitirá explorar questões impossíveis de serem reproduzidas em laboratório. Do ponto de vista prático, temos um parceiro de pesquisa bastante disposto a colaborar, pelo benefício que ele próprio enxerga que a pesquisa poderá retornar para ele.

Há contudo implicações éticas que precisam ser consideradas e submetidas ao Comitê de Ética desta instituição, que envolvem o trato próximo com um indivíduo fragilizado por conta de uma deficiência física e a interferência direta em algumas de suas condições de vida, como requisitos necessários para a realização deste trabalho de pesquisa. Como em toda pesquisa tecnológica, há riscos e compromissos inerentes à atividade investigativa, sobre os quais nossos melhores esforços serão empreendidos no sentido de previamente avaliar, ponderar e prevenir exposições que vão além das que já fazem parte do cotidiano comum. Em troca de sua colaboração até o final, o DI cederá para o Usuário Principal as tecnologias desenvolvidas ao longo do projeto. Toda tecnologia será necessariamente adaptada às suas condições e dimensões corporais. Assim, os equipamentos e materiais serão talhados para o uso de um único usuário, e não serão adequados para uso de qualquer outra pessoa. Por isto, é natural – além de vantajoso – deixá-lo disponível para uso do Usuário Principal.

---

[2] De agora em diante, iremos nos referir a esta pessoa como *Usuário Principal* para manter o anonimato dele e das demais pessoas relacionadas a ele envolvidas no estudo.

Consideramos o projeto de baixo risco para o participante em questão. As tecnologias a serem utilizadas são comuns e já estão presentes em diversos equipamentos que cercam o seu cotidiano (microcomputadores, telefones celulares, televisores, *tablets*, internet, etc.). Além disso, não se pretende com elas interferir em atividades ligadas a sua saúde ou sobrevivência (ex: alimentação e higiene pessoal), terapêuticas, ou de forma irreversível em nenhuma atividade do seu cotidiano. A princípio, consideramos que os benefícios decorrentes diretamente do uso das tecnologias a serem desenvolvidas superarão a adição dos riscos, que podem ir bem pouco além dos já enfrentados normalmente por ele em seu dia-a-dia ao utilizar seu computador e a internet, por exemplo. Tais aspectos serão melhor discutidos na seção 6.2.

4 Objetivos

Dentro deste panorama mais geral de interesse central do pesquisador principal do projeto, fez-se inicialmente um estudo dirigido durante 6 meses sob orientação dos mesmos professores orientadores do projeto aqui descrito, onde buscou-se definir um escopo de trabalho factível em termos de prazo, complexidade e nível de exigência compatíveis com o curso de Mestrado em Informática do Departamento de Informática da PUC-Rio. Durante este período, pesquisou-se sobre o panorama geral de Tecnologia Assistiva no país e internacionalmente, bem como sobre outras tecnologias relacionadas, além de revisão bibliográfica sobre temas relacionados e metodologias em IHC. Além disso, neste período tivemos um contato preliminar com o futuro usuário da Tecnologia Assistiva a ser desenvolvida. Familiarizamo-nos com situações cotidianas em seu ambiente doméstico e ao desempenhar atividades escolares e profissionais. Com o consentimento preliminar do Usuário Principal, bem como o de outros participantes presentes no contexto do contato (familiares, enfermeiros, empregados domésticos e terapeutas), tomamos conhecimento inicial das necessidades e requisitos gerais para um projeto de pesquisa tal como o que se apresenta aqui. Visamos os seguintes objetivos concretos:

- *Desenvolver dispositivos baseados nas tecnologias da Internet das Coisas para assistir uma pessoa com limitação funcional física severa a interagir com o seu ambiente doméstico e no desempenho de suas atividades escolares e profissionais;*
- *Realizar a prototipação e o estudo de um ambiente de configuração e programação da tecnologia desenvolvida acima de modo que uma customização da mesma possa ser realizada pelo próprio usuário, e/ou seus assistentes e familiares;*
- *Avaliar os sistemas desenvolvidos e estudar as experiências dos usuários no uso das ferramentas providas, bem como as possíveis linhas de evolução na adoção deste tipo de tecnologia por parte deles.*

Dos objetivos expostos acima, derivam-se as seguintes atividades:

- *Em relação ao desenvolvimento de dispositivos baseados nas tecnologias da Internet das Coisas:*

- Desenvolvimento de dispositivos de interação do tipo *wearable computers*[3], apropriados às possibilidades e limitações do participante;
- Desenvolvimento de dispositivos de conexão capazes de traduzir ações e intenções do usuário, captadas pelos dispositivos de interação acima, em comandos para aparelhos comuns (*i.e.*, não adaptados) ao seu redor, como por exemplo: sua televisão, seu computador, etc.

- *Em relação à prototipação e estudo de um ambiente de configuração e programação:*
  - *Design* do ambiente em suas funções, arquitetura e interações, incluindo a modelagem de usuário e tarefas e o mapeamento destes modelos em requisitos e opções de projeto funcionais, de interface e de interação;
  - Prototipação, avaliação dos protótipos e refinamento da solução até a disponibilização de uma versão "final" do ambiente;

- *Em relação à avaliação dos sistemas desenvolvidos e estudo das experiências dos usuários:*
  - Testes acompanhados do sistema com o Usuário Principal;
  - Instrumentação do sistema para acompanhar sua utilização cotidiana;
  - Avaliação dos sistemas desenvolvidos com especialistas de área de tecnologia (IHC) e profissionais ou cuidadores que lidam com pessoas com o perfil do Usuário Principal desta pesquisa.

5 Metodologia

Apresentamos a seguir a metodologia de pesquisa a ser adotada e suas justificativas principais.

5.1 Pesquisa qualitativa

A pesquisa que pretendemos desenvolver necessita de um domínio a ser estudado e pretende estabelecer observações partindo de um caso específico que possa ser estendido ou que tenha implicações relevantes para um conhecimento mais geral em circunstâncias semelhantes, como comumente ocorre em uma pesquisa qualitativa. No campo da pesquisa sobre deficiência, as metodologias qualitativas surgiram como uma das ferramentas mais importantes na compreensão das complexidades das deficiências em seus contextos sociais (O'Day & Killeen, 2002). O pesquisador tenta compreender a experiência dos participantes a partir de um ponto de vista interno ao contexto (*insider*) e, ao fazer isso, ele busca desenvolver uma firme compreensão das dimensões básicas dos temas em questão e muitas vezes ir além

[3] *Wearable computers* se referem a micro-processadores computacionais, flexíveis, que se podem embutir em roupas, adereços e objetos pessoais. São, por isso, computadores *"vestíveis"* e uma das tecnologias relacionadas à Internet das Coisas.

do conhecimento convencional e de noções preconcebidas. O resultado é que as suas conclusões são baseadas nas realidades da vida cotidiana e podem fornecer o tipo de conhecimento que tem uso imediato e prático (O'Day & Killeen, 2002).

Sobre o uso de pesquisa qualitativa em Computação nos diz (Filippo & Fuks, 2008, p. 31):

“A argumentação em favor do uso de métodos qualitativos é que através destes métodos o pesquisador é capaz de ter uma compreensão aprofundada do sistema quando em operação num ambiente complexo. Através de métodos como estudos de caso e etnografia, o pesquisador observa o ambiente, realiza entrevistas, filma, entre outros. Ao aprender sobre o ambiente, ele se torna capaz de identificar as diversas variáveis envolvidas, relacioná-las com seu contexto, descobrir detalhes intrincados e identificar diferentes interpretações para um mesmo fato.”

5.2 Pesquisa-ação

Dentre os métodos qualitativos propostos para realizar investigações sobre o uso de sistemas computacionais num ambiente real, a pesquisa-ação é um deles (Filippo & Fuks, 2008, p. 31). Segundo (Kock, 2013), a pesquisa-ação é um nome genérico usado para se referir a um conjunto de abordagens de pesquisa que possuem algumas características em comum, a saber: na pesquisa-ação o pesquisador geralmente tenta fornecer um serviço a um "cliente" de pesquisa e, ao mesmo tempo, aumentar o corpo de conhecimento em um domínio particular. Ainda de acordo com ele, no contexto da tecnologia, pode ser o estudo de como a tecnologia é aplicada no mundo real e das consequências práticas da ação suportada pela tecnologia. Um exemplo seria o pesquisador introduzindo uma nova tecnologia em um contexto de uso, e ao mesmo tempo estudando os seus efeitos neste contexto. A ênfase pode estar na concepção da tecnologia, na avaliação empírica dos efeitos da tecnologia, ou em ambos os aspectos.

A pesquisa-ação permite partir-se de um problema específico identificado em um ambiente real, e que o pesquisador atue e faça parte do ambiente da pesquisa, relatando suas impressões sobre o problema e sobre as soluções investigadas. Busca-se avançar na teoria atuando na prática, o que é feito através de ações no contexto do problema estudado. O foco do pesquisador é na compreensão do problema e das ações realizadas para solucioná-lo dentro de um ambiente real particular e não na verificação de uma hipótese de caráter geral num ambiente de laboratório. Além disso, a pesquisa-ação permite que pesquisadores e “pesquisados” colaborem visando compreender um problema, as ações propostas para solucioná-lo adequadamente e o efeito destas ações (Filippo & Fuks, 2008, p. 25 et seq.).

Nesta pesquisa buscaremos avaliar ferramentas tecnológicas a serem desenvolvidas investigando-se como usuários, dentro do seu contexto, usam e são influenciados por elas, bem como considerando a sua colaboração no design das mesmas, o que torna a pesquisa-ação adequada para os objetivos deste trabalho. Contudo, a fronteira entre este e outros métodos não é exata (Kock, 2013), e deixamos aberta a possibilidade de diálogo e interlocução entre este e outros métodos durante o projeto – como por exemplo, a Etnografia – o que aliás é sugerido e aconselhado em trabalhos de pesquisa qualitativa (Neves, 2006).

5.3 Participantes

O envolvimento de participantes é uma prática corriqueira e amplamente utilizada nas pesquisas de IHC (também chamados de "sujeitos", normalmente os "usuários" de alguma tecnologia sob investigação). Os objetivos e foco da pesquisa variam em torno de se realizar um grupo de foco, um processo de design colaborativo, um estudo controlado, ou uma investigação etnográfica, mas quase invariavelmente necessitam do envolvimento de pessoas no trabalho (Lazar, et al., 2010, p. 368).

Numa pesquisa envolvendo portadores de deficiência, essa questão é ainda mais importante:

"The goals of HCI[4] research on users with impairments are the same as research with other users, understand the phenomena surrounding computer interfaces and usage patterns. Because the users have a complex story, it is important to involve those individuals in HCI research, design, and evaluation. You can't just take guidelines from the research on interface design for people with impairments, and you can't just take proxy users that represent the users with impairments. You must work with users with impairments themselves." (Lazar, et al., 2010, p. 400)

Ao mesmo tempo, há dificuldades práticas para se trabalhar com esta população:

"Finding a suitably large participant pool can be particularly challenging for research involving people with disabilities. In addition to being an often-overlooked segment of society, people with disabilities often face significant challenges in transportation, making trips to research labs difficult. Studies with these users are often smaller, tending towards observational case studies with two or three users, rather than controlled experiments." (Lazar, et al., 2010, p. 372)

E assim a comunidade científica tem conduzido esta questão:

"The generally accepted approaches for dealing with the issue of access to appropriate participants for research focusing on users with impairments are small sample sizes, distributed research, and in-depth case studies. Choosing the most appropriate approach will depend on the nature of the research questions." (Lazar, et al., 2010, p. 401)

[4] A sigla HCI significa Humam-Computer Interaction, *i.e.*, o termo em inglês para Interação Humano-Computador (IHC).

O que iremos realizar será um estudo em profundidade, investigando uma população reduzida de participantes, envolvidos conjuntamente em um contexto bastante específico de vida. Apesar de nosso "usuário de tecnologia" ser uma pessoa única, o Usuário Principal é acompanhado cotidianamente por enfermeiros e/ou familiares, que o auxiliam no seu transporte, atividades da vida cotidiana e sobrevivência, dada a sua condição. Ainda que estejamos desenvolvendo tecnologia somente para seu uso, aproveitaremos este fato para abordar os cuidadores e familiares, pessoas do seu círculo próximo e com conhecimento sobre ele e sobre suas condições. Também pretendemos entrevistar profissionais da área de saúde que lidam com pessoas com o perfil do Usuário Principal. Eles serão entrevistados (e ocasionalmente observados a examinar ou testar a tecnologia assistiva que estaremos desenvolvendo), de modo a obtermos dados complementares para esclarecer, aprofundar, validar ou rejeitar as respostas para as nossas questões de pesquisa, nos permitindo o confronto e elicitação dos dados.

5.4 Coleta e análise dos dados

Serão utilizadas uma combinação de métodos e técnicas de design e avaliação de IHC adequadas e legitimadas para cada atividade, a maioria das quais bem descritas em (Barbosa & da Silva, 2010). Usaremos técnicas de entrevistas de explicitação e análise de discurso para coletar e interpretar *relatos das experiências dos usuários* (Light, 2006). Além disso, a observação dos participantes proporciona ao pesquisador a compreensão da *sensação do que é ser o outro*, para com isso ter acesso às experiências dos usuários através da construção de *empatia* (Wright & McCarthy, 2008).

Os dados serão coletados através de anotações do pesquisador (“diário de pesquisa”), fotografias, gravações de áudio e transcrições (entrevistas), vídeos (quando aplicáveis) e dados dos sistemas utilizados (ex: *logs* e/ou sequências de telas), sempre com o consentimento dos participantes. Do ponto de vista científico, estes dados consistirão material empírico e evidências da pesquisa realizada. Como é de praxe neste tipo de pesquisa qualitativa, onde não podemos controlar as condições em que os dados são coletados, tampouco garantir a sua reprodutibilidade, para garantir a consistência teórica e prática da pesquisa, os detalhes do processo de coleta e as evidências serão oferecidos quando da publicação dos resultados, para que os leitores possam formar seu próprio juízo a respeito destes.

6 Plano de Trabalho

Este projeto se propõe a ser desenvolvido dentro do prazo normal para conclusão do curso de Mestrado em Informática da PUC-Rio, que é de 18 meses até a defesa da proposta de dissertação e 6 meses adicionais para a pesquisa e conclusão da dissertação (Coordenação de Pós-Graduação - Departamento de Informática - PUC-Rio, 2013). Estou apresentando esta proposta de pesquisa no início de meu 13º mês do programa de mestrado, antecipando o

Exame de Proposta de Dissertação (até o 18º mês) e o início da atividade de pesquisa (que se estende até o 24º mês). Assim sendo, as atividades foram programadas de modo a serem compatíveis com este contexto. A seguir apresentam-se cronograma e os custos previstos.

6.1 Cronograma

Em suas atividades principais, o projeto deverá transcorrer aproximadamente como abaixo:

	1o. Semestre						2o. Semestre						3o. Semestre						4o. Semestre					
	jul/13	ago/13	set/13	out/13	nov/13	dez/13	jan/14	fev/14	mar/14	abr/14	mai/14	jun/14	jul/14	ago/14	set/14	out/14	nov/14	dez/14	jan/15	fev/15	mar/15	abr/15	mai/15	jun/15
Etapa 0: Início do curso																								
- Realização de disciplinas obrigatótias																								
Etapa 1: Estudo preliminar																								
- Obervação e entrevistas de reconhecimento																								
- Identificação de necessidades e requisitos																								
- Elaboração do protocolo de pesquisa																								
Etapa 2: Prototipação																								
- Dispositivo de interação																								
- Hub de conexão																								
- Ambiente de configuração e programação																								
Etapa 3: Avaliação																								
- Avaliação dos sistemas																								
- Experimentação com os usuários																								
- Análise dos dados																								
Etapa 4: Conclusão																								
- Refinamentos finais																								
- Conclusões do estudo																								
- Defesa da dissertação																								

Legenda:
Não envolvimento de participantes
Envolvimento esporádico participantes
Envolvimento médio de participantes
Envolvimento intenso de participantes

6.2 Orçamento

O projeto conta com a participação de um pesquisador principal e seus dois professores orientadores. Não há orçamento previsto especificamente para este projeto além dos contratos de trabalho dos professores envolvidos, bolsas de pesquisa e produtividade de que já dispõe e financiamento acadêmico normal do programa de pós-graduação do DI/PUC-Rio. Além destes, haverá os seguintes os custos específicos com equipamentos neste projeto:

Item	Valor	Fonte do recurso
Headset Sennheiser SD Office 1	~R$ 1.000,00	*Bolsa de pesquisa da Prof. Clarisse Sieckenius de Souza*
Microcontroladores, sensores e componentes para prototipação	~R$ 1.000,00	*Disponível para uso no Laboratório "Second Lab" do DI - Prof. Hugo Fuks*

7 Aspectos Éticos do Projeto

Desde a fase de concepção do projeto, o pesquisador principal mostra-se atento às questões éticas de seu trabalho, conforme direcionado pelos seus professores orientadores, aprendendo a ver que o processo de introdução de tecnologia, seja em uma organização ou na vida das pessoas, tem o potencial de gerar mudanças individuais, psicológicas e sociais profundas, dado que interfere nas formas de as pessoas agirem, se comunicarem umas com as outras e se relacionarem como mundo ao seu redor. Aliás, esta é inclusive umas das dimensões de interesse da própria IHC, que se preocupa em investigar quais são estas interferências, como elas se processam, e por quais as razões, bem como que aspectos da tecnologia a influenciam, apenas para citar alguns aspectos de interesse científico desta comunidade. Quando esta interferência tem o potencial de ir além dos laboratórios da universidade, como aliás ocorre na maioria (se não em todas) as pesquisas tecnológicas, se faz necessário uma reflexão contínua sobre a ética do objeto a ser construído e dos métodos a serem utilizados.

Dito isto, entendemos que este projeto merece uma reflexão ética sobre quatro dimensões:

- *Sobre os seus objetivos, e o valor dos mesmos;*
- *Sobre os seus produtos, e as possíveis consequências dos seus usos;*
- *Sobre os seus métodos, e a validade científica dos possíveis resultados;*
- *Sobre os seus procedimentos, especificamente no que diz respeito à pesquisa envolvendo seres humanos.*

7.1 A Ética nos objetivos do projeto

Acreditamos que seja social e cientificamente relevante produzir avanços científicos e tecnológicos no domínio da Tecnologia Assistiva. Este objetivo é corroborado e está em sintonia com políticas públicas atuais no mundo e em nosso país, que buscam promover a inclusão integral do portador de deficiência na sociedade, onde inclusive o desenvolvimento, a disponibilização e o acesso à Tecnologia Assistiva tem um papel de destaque (BRASIL - Presidência da República, 2011); (Secretaria de Direitos Humanos da Presidência da República (SDH/PR) / Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência (SNPD), 2013). Ao mesmo tempo, desenvolvimentos relacionados ao *End-User Development* e Internet das Coisas são avanços tecnológicos e científicos de interesse para sociedade. Não enxergamos, até o momento, se e como tais objetivos seriam prejudiciais a alguma parcela da sociedade.

7.2 A Ética nos produtos do projeto

Sem discutir as implicações relacionadas ao uso e adoção de tecnologia na sociedade atual em suas diversas facetas, assumimos que os produtos tangíveis produzidos por nossa pesquisa não introduzem questões adicionais às já enfrentadas em nosso dia-a-dia, com os produtos de tecnologia já existentes e usados amplamente a nossa volta. Devemos, no entanto, estar sensíveis às discussões sobre os efeitos tanto das tecnologias atuais como das modificações ou modos de utilização que viermos a promover com a nossa pesquisa. Para isso, contamos com fatores que, acreditamos, tornam esta reflexão possível e nos dão segurança para a condução deste trabalho de forma ética:

- *A sólida experiência em pesquisa e formação dos professores orientadores em Ciência da Computação e especificamente na área de Interação Humano-Computador, o que imprime ao projeto um olhar atento e cuidadoso para os usuários;*
- *A interação constante com outros pesquisadores experientes nestes dois assuntos através de seminários dos grupos de pesquisa coordenados pelos professores orientadores deste projeto, que possibilita a troca de experiências e a avaliação de decisões de projeto por outros pontos de vista, externos ao projeto, além de contribuírem com conhecimentos e reflexões adicionais;*
- *A submissão do projeto ao sistema CEP/CONEP, com o objetivo de que este possa dar o seu parecer de um ponto de vista ainda mais externo e especializado nesta questão.*

7.3 A Ética nos métodos e validade científica dos resultados

Como uma pesquisa qualitativa, não pretendemos obter, a princípio, resultados estatisticamente significativos ou leis generalizáveis com este trabalho. Em uma pergunta, nossa questão principal poderia ser sintetizada da seguinte forma: *como a capacidade de* *customizar tecnologia pode proporcionar uma melhor experiência de uso e acesso para um usuário com restrições físicas severas?* Nosso estudo investigará temas relevantes para a IHC, de modo geral, e também para as linhas de pesquisa do *End-User Development*, Internet das Coisas/*Wearable Computers* e Tecnologia Assistiva. Mas ao invés de se buscar regras universais ou sempre válidas para algum contexto, esperamos obter um entendimento aprofundado e empiricamente embasado sobre as motivações, dificuldades, limitações e possíveis soluções relacionadas ao uso deste tipo de tecnologia num único contexto. Se este entendimento pode ou não ser generalizado, caberá a outros estudos posteriores investigar. Mas certamente apresentaremos questões reais para instigar e avançar a pesquisa nestas linhas, uma vez que serão frutos da nossa observação de fatos concretos. Esperamos que tais questões possam interessar à comunidade científica, através de uma continuação ou de estudos complementares.

A coleta e análise dos dados em semelhante tipo de trabalho é uma questão importante. Além do já descrito na seção 5.4, seguiremos as recomendações padrão de uma pesquisa qualitativa que busca a qualidade ao envolver observação e entrevistas de participantes em campo:

- *Postura observadora, aberta e investigativa;*
- *Design cuidadoso das entrevistas e dos experimentos, de modo a não induzir respostas;*
- *Descrição das influências internas (ex: do pesquisador) e externas (ex: do ambiente);*
- *Descrição dos procedimentos adotados junto aos resultados para juízo dos leitores.*

7.4 A Ética nos procedimentos de uma pesquisa envolvendo seres humanos

Os participantes da pesquisa compreendem uma população que envolverá de 3 a 10 indivíduos, incluindo um portador de tetraplegia e pessoas de seu círculo próximo, como cuidadores e familiares (ver seções 3 e 5.3). Todos são maiores de idade, plenamente autônomos, de classes sociais média e baixa, com profissões e papéis variados: temos o Usuário Principal, que é estudante, seus enfermeiros, familiares, empregados domésticos e, eventualmente, médicos e terapeutas que o atendem em casa. As pessoas serão envolvidas através de observação e/ou entrevistas, realizadas em campo, ou seja, nos seus próprios locais de residência, trabalho e estudo para sua maior comodidade, dado as limitações do participante principal, sempre com marcação antecipada, respeitando-se a conveniência, disponibilidade e vontade de cada um. Com isso, teremos acesso aos seus ambientes cotidianos naturais. Este acesso será limitado ao pesquisador principal e em horários convencionais sempre que possível, de modo a minimizar os incômodos causados por uma pessoa externa nestes locais. Caso isso não seja possível por algum motivo, alternativas serão cuidadosamente negociadas, respeitando-se a possibilidade e a vontade dos participantes em primeiro lugar.

As informações de interesse são essencialmente relacionadas à interação com a tecnologia a ser desenvolvida e o ambiente ao redor: busca-se essencialmente identificar e analisar as facilidades e dificuldades da tecnologia, bem como pontos de vista e sugestões dos participantes. Como o conceito de *experiência do usuário* é amplo, informações relacionadas a opiniões, condições e estados físicos e psicológicos também serão coletadas e analisadas.

Dada a natureza da pesquisa, os participantes serão envolvidos durante um período longo de tempo, em torno de 1 ano, de forma esporádica, conforme necessidade, na maior parte deste tempo. Mas haverá períodos em que serão necessárias participações mais frequentes, no momento de se testar e avaliar as tecnologias desenvolvidas. Mesmo nestes períodos, tentar-se-á não fazer mais do que uma sessão por semana. As sessões de observação e entrevistas poderão ser particularmente longas (ex: > 2 horas), pela natureza dos objetivos e também pelas características e limitações do Usuário Principal. Isso será sempre negociado previamente, respeitando-se a vontade e disponibilidade dos participantes em primeiro lugar.

Os riscos destes estudos são pequenos e ligados, principalmente, ao desconforto físico devido a movimentos repetitivos ou ao estado psicológico do usuário ou outro participante. Eventualmente, pode-se adicionar riscos de segurança digital ao se introduzir mais pontos de conexão com a internet em seu ambiente doméstico. Estes não serão maiores do que os já enfrentados normalmente por qualquer usuário de internet em sua casa, com vários dispositivos ligados a um ponto de acesso. Haverá acesso a alguma privacidade pessoal (usuário e familiares) e profissional (cuidadores) em algum grau. Estes riscos serão minimizados e administrados da seguinte forma:

- *A explicação detalhada dos objetivos e das etapas da pesquisa para os participantes;*
- *A apresentação dos equipamentos, instruções de uso e seus riscos envolvidos de forma clara e detalhada para os participantes de modo a permitir suas decisões informadas;*
- *A garantia do anonimato das informações colhidas por meio de quaisquer métodos e técnicas (entrevistas, questionários, observações de campo, coleta de dados automática do sistema, etc.) e, em particular, a garantia da preservação da imagem nos casos em que se recorra a fotografias ou vídeos de um ou mais participantes;*
- *A descrição dos instrumentos de coleta usados na pesquisa (gravador, filmadora, computador, etc.), acompanhada das razões para sua utilização;*
- *O caráter voluntário de participação na pesquisa e a possibilidade de interromper temporária ou definitivamente esta participação a qualquer momento;*
- *A leitura e a assinatura do "Termo de Consentimento" (ver* Anexo I – Termo de Consentimento Livre e Esclarecido*), emitido em duas vias, após a explicação oral e informal dos tópicos acima*[5]*;*

[5] A assinatura é substituída por uma impressão digital no caso de um portador de tetraplegia, que é feita com o auxílio de um ajudante, como é de costume nestes casos.

- *Execução da pesquisa propriamente dita, conduzida por um único pesquisador principal da equipe, de forma supervisionada pelos seus professores orientadores;*
- *O oferecimento de acesso às publicações científicas futuras resultantes da pesquisa da qual o entrevistado participou.*

Além disso, vale ressaltar que sempre que se envolver o usuário, o mesmo estará acompanhado por um de seus cuidadores, terapeutas ou familiares, o que oferece segurança adicional para o trato com ele, uma vez que estas pessoas são cientes e preparadas para lhe dar com as suas limitações.

Há ainda o risco de interrupção do trabalho por parte dos participantes ou da equipe: o Usuário Principal pode desistir ou desejar interromper o trabalho por qualquer motivo; um participante que acompanha o usuário pode ser trocado; um ou mais dos pesquisadores podem tomar outros rumos. Apesar de estarmos falando de um horizonte de tempo relativamente curto (em torno de um ano), iremos endereçar essa questão da seguinte forma:

- *Em caso de interrupção por parte do participante principal, iremos procurar pessoa ou instituição semelhante para finalização do trabalho. Se isso não for possível ou não houver mais prazo, a pesquisa será concluída sem ênfase em Tecnologia Assistiva;*
- *A troca de um enfermeiro ou cuidador por outro atende as necessidades da pesquisa da mesma forma, e não invalida nem inviabiliza o trabalho;*
- *No caso de interrupção por parte dos pesquisadores, os equipamentos adquiridos e desenvolvidos até o momento da interrupção serão cedidos para o participante Usuário Principal.*

Não haverá necessidade de ressarcimento de despesas para o Usuário Principal da tecnologia (ou outros envolvidos) uma vez que a equipe de pesquisa tomará todas as providências para poupar deslocamentos dos envolvidos e fornecerá os materiais e demais recursos necessários para a prototipação, instalação e uso da tecnologia proposta.

Ao final do projeto, a equipe deixará os equipamentos adquiridos e desenvolvidos para o Usuário Principal que participou da pesquisa. O fato de os equipamentos ter de serem a tal ponto personalizados tornará impraticável aproveitá-los com outra pessoa. Além disso, seria questionável a conduta de indisponibilizar um equipamento personalizado e útil para uma pessoa com deficiência uma vez que o pesquisador logrou o seu intuito com a pesquisa. Entendemos que, embora não se trate de uma compensação material para o participante, trata-se indiscutivelmente de uma vantagem de participação. E, nesta situação, devemos nos precaver contra a possibilidade de o participante inconscientemente (ou não) passar a filtrar informações que ele presuma que poriam em risco os rumos de pesquisa para preservar as vantagens que vê nela. Concretamente, utilizaremos dois recursos principais: o uso sistemático de um método de entrevista que foi especialmente desenhado para tratar da tendência de usuários “agradarem a entrevistadores” ao falarem do uso de tecnologias por eles desenvolvidas (Light, 2006); a entrevista com profissionais de saúde especializados no trato de pacientes com tetraplegia, mas que não estão no círculo de relações do participante central da pesquisa.

8 Referências

Atzori, L., Iera, A. & Morabito, G., 2010. The Internet of Things: A survey. *Computer Networks,* Volume 54, pp. 2787 - 2805.

Auto-ID Labs, s.d. *MIT, University of Cambridge, ETH Zurich / HSG, Fudan University, Keio University, KAIST, University of Adelaide.* [Online]
Disponível em: http://www.autoidlabs.org/
[Acesso em 16 julho 2014].

Barbosa, S. D. J. & da Silva, B. S., 2010. *Interação Humano-Computador.* Rio de Janeiro: Elsevier-Campus.

BNDES - Banco Nacional do Desenvolvimento, 2014. *Seminário "Internet das Coisas: Oportunidades e Perspectivas da Nova Revolução Digital para o Brasil" - 14 e 15 de maio de 2014.* [Online]
Disponível em:
http://www.bndes.gov.br/SiteBNDES/bndes/bndes_pt/Institucional/Sala_de_Imprensa/Notas/2014/20140513_internetdascoisas.html
[Acesso em 29 maio 2014].

BRASIL - Presidência da República, 1999. *DECRETO Nº 3.298, DE 20 DE DEZEMBRO DE 1999.* [Online]
Disponível em: http://www.planalto.gov.br/ccivil_03/decreto/d3298.htm
[Acesso em 29 maio 2014].

BRASIL - Presidência da República, 2011. *DECRETO Nº 7.612, DE 17 DE NOVEMBRO DE 2011.* [Online]
Disponível em: http://www.planalto.gov.br/ccivil_03/_Ato2011-2014/2011/Decreto/D7612.htm
[Acesso em 30 jul. 2014].

COMISSÃO NACIONAL DE ÉTICA EM PESQUISA - CONSELHO NACIONAL DE SAÚDE - MINISTÉRIO DA SAÚDE, 2012. *RESOLUÇÃO Nº196/96 versão 2012.* [Online]
Disponível em:
http://conselho.saude.gov.br/web_comissoes/conep/aquivos/resolucoes/23_out_versao_final_196_ENCEP2012.pdf
[Acesso em 22 jul. 2014].

Coordenação de Pós-Graduação - Departamento de Informática - PUC-Rio, 2013. *Regulamento dos Programas de Pós-Graduaça o Stricto Sensu do Departamento de Informática.* [Online]
Disponível em: http://www.inf.puc-rio.br/wp-content/uploads/2013/05/regulamento-PG-DI-2013-10-04.pdf
[Acesso em 29 jul. 2014].

de Souza, C. S. & Barbosa, S. D. J., 2006. A semiotic framing for end-user development. In: H. Lieberman, F. Paternò & V. Wulf, eds. *End User Development.* New York: Springer, pp. 401-426.

Filippo, D. D. R. & Fuks, H., 2008. *Suporte à coordenação em sistemas colaborativos: uma pesquisa-ação com aprendizes e mediadores atuando em fóruns de discussão de um curso a distância.* Rio de Janeiro: Tese de Doutorado - Departamento de Informática, Pontifícia Universidade Católica do Rio de Janeiro.

Galvão Filho, T. A., 2009. A Tecnologia Assistiva: de que se trata?. In: G. J. C. Machado & M. N. Sobral, eds. *Conexões: educação, comunicação, inclusão e interculturalidade.* Porto Alegre: Redes Editora, pp. 207-235.

Glinert, E. P. & York, B. W., 1992/2008. Computers and People with Disabilities. *ACM Transactions on Accessible Computing,* 10/2008, Volume 1, No. 2, pp. 1-7.

IBGE - Instituto Brasileiro de Geografia e Estatística, 2010. *Censo Demográfico 2010: Características gerais da população, religião e pessoas com deficiência.* [Online]
Disponível em:
http://www.ibge.gov.br/home/estatistica/populacao/censo2010/caracteristicas_religiao_deficiencia/default_caracteristicas_religiao_deficiencia.shtm
[Acesso em 27 maio 2014].

ITU - International Telecommunication Union, 2005. *ITU Internet Reports - The Internet of Things.* [Online]
Disponível em: http://www.itu.int/wsis/tunis/newsroom/stats/The-Internet-of-Things-2005.pdf
[Acesso em 16 julho 16].

Kock, N., 2013. Action Research: Its Nature and Relationship to Human-Computer Interaction. In: M. Soegaard & R. F. Dam, eds. *The Encyclopedia of Human-Computer Interaction.* 2nd ed. Aarhus: The Interaction Design Foundation.

Kopetz, H., 2011. Internet of Things. In: H. Kopetz, ed. *Real-Time Systems: Design Principles for Distributed Embedded Applications.* New York, NY: Springer, pp. 307-323.

Ladner, R. E., 2008. Access and Empowerment: Commentary on "Computers and People with Disabilities". *ACM Transactions on Accessible Computing,* 10/2008, Volume 1, No. 2, pp. 1-5.

Lazar, J., Feng, J. H. & Hochheiser, H., 2010. *Research Methods in Human-Computer Interaction.* Chichester, West Sussex, UK: John Wiley & Sons Ltd.

Lieberman, H., Paterno, F., Klann, M. & Wulf, V., 2006. End-user development: An emerging paradigm. In: H. Lieberman, F. Paterno & V. Wulf, eds. *End User Development.* New York: Springer, pp. 1-8.

Light, A., 2006. Adding method to meaning: a technique for exploring peoples' experience with technology. *Behaviour & Information Technology,* Volume 25, no. 2, p. 175– 187.

Neves, V. F. A., 2006. Pesquisa-ação e Etnografia: Caminhos Cruzados. *Pesquisas e Práticas Psicossociais,* jun./2006.Volume 1, n. 1, São João del-Rei.

O'Day, B. & Killeen, M., 2002. Research on the Lives of Persons with Disabilities: The Emerging Importance of Qualitative Research Methodologies. *Journal of Disability Policy Studies,* Volume 13 no. 1, pp. 9-15.

ONU - Organização das Nações Unidas, s.d. *A ONU e as pessoas com deficiência.* [Online] Disponível em: http://www.onu.org.br/a-onu-em-acao/a-onu-e-as-pessoas-com-deficiencia/ [Acesso em 29 maio 2014].

Secretaria de Direitos Humanos da Presidência da República (SDH/PR) / Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência (SNPD), 2012. *Cartilha do Censo 2010 – Pessoas com Deficiência.* Brasília: SDH-PR/SNPD. Disponível em: http://www.sdh.gov.br/assuntos/pessoa-com-deficiencia/dados-estatisticos/pesquisas-demograficas [Acesso em 29 maio 2014].

Secretaria de Direitos Humanos da Presidência da República (SDH/PR) / Secretaria Nacional de Promoção dos Direitos da Pessoa com Deficiência (SNPD), 2013. *VIVER SEM LIMITE – Plano Nacional dos Direitos da Pessoa com Deficiência.* Brasília: SDH-PR/SNPD. Disponível em: http://www.pessoacomdeficiencia.gov.br/app/sites/default/files/arquivos/%5Bfield_generico_imagens-filefield-description%5D_0.pdf [Acesso em 30 jul. 2014].

Vanderheiden, G. C., 2007. Redefining assistive technology, accessibility and disability based on recent technical advances. *Journal of Technology in Human Services,* Volume 25, No. 1/2, pp. 147 - 158.

Vanderheiden, G. C., 2012. Design for People with Functional Limitations. In: G. Salvendy, ed. *Handbook of human factors and ergonomics.* Hoboken, NJ, USA: Wiley, pp. 1409-1441.

Vega, K. & Fuks, H., 2013. *Beauty technology as an interactive computing platform.* Proceedings of the 2013 ACM international conference on Interactive tabletops and surfaces, St Andrews, UK, ACM, pp. 357-360.

Wikipedia - Português, 2014. *Internet das Coisas.* [Online]
Disponível em: http://pt.wikipedia.org/wiki/Internet_das_Coisas
[Acesso em 29 maio 2014].

Wright, P. & McCarthy, J., 2008. *Empathy and experience in HCI.* 26th Conference on Human Factors in Computing Systems - Proceedings CHI '08, Florence, Italy, Elsevier, p. 637–646.

Anexo I – Termo de Consentimento Livre e Esclarecido

TERMO DE CONSENTIMENTO

Título da pesquisa: *End-User Development* aplicado à Tecnologia Assistiva

Pesquisador: Bruno Azevedo Chagas (Mestrando DI / PUC-Rio) - bchagas@inf.puc-rio.br
Departamento de Informática, PUC-Rio
R. Marques de São Vicente 225, Gávea
CEP 22451-900 - Rio de Janeiro, RJ - Brasil
Tel: (21) 3527-1500 / Fax: (21) 3527-1530 / Cel: (21) 98475-7696
Orientadores: Profs. Hugo Fuks (hugo@inf.puc-rio.br – Cel: (21) 98111-7109) e Clarisse Sieckenius de Souza (clarisse@inf.puc-rio.br – Cel: (21) 99919-2712)

Participante: ______________________________________

Caro(a) participante,

Desenvolvemos aqui no Departamento de Informática da PUC-Rio diversas pesquisas na área da Interação Humano-Computador (IHC) que estuda teorias, métodos e tecnologias para projeto, avaliação e implementação de sistemas interativos, bem como dos fenômenos ao redor deles. Com grande honra gostaríamos de convidar você para participar de nossa pesquisa, que busca unir as linhas de pesquisa de *End-User Development* e Internet das Coisas para desenvolver avanços científicos e tecnológicos no domínio da Tecnologia Assistiva.

Propósito: O objetivo desta pesquisa é entender como a capacidade de customizar tecnologia pode proporcionar uma melhor experiência de uso e acesso para um usuário com restrições físicas severas. Participantes serão solicitados a utilizar um dispositivo de interação e software especial para controlar seu computador e aparelhos ao seu redor, como sua TV ou rádio. A realização das tarefas será observada e faremos algumas entrevistas sobre as impressões ao se utilizar o sistema que nos fornecerão dados para determinar se e como a tecnologia desenvolvida pode oferecer benefícios neste contexto.

Procedimentos: A participação neste estudo irá envolver três tipos de atividades. Primeiramente, você será entrevistado e observado no que diz respeito às suas necessidades, dificuldades e hábitos de interação com aparelhos, ambientes e pessoas ao seu redor. Isso será feito com o objetivo de que possamos coletar dados que direcionarão o desenvolvimento da tecnologia que nos propomos a construir.

Depois disso, observaremos a utilização do sistema desenvolvido. Você poderá ser solicitado a utilizar o sistema, ou simplesmente observar como um outro usuário próximo a você o utiliza.

Finalmente, ao final, poderemos questionar as suas impressões, opiniões, sensações e percepções sobre atividades realizadas e a tecnologia utilizada.

Coleta de dados: Faremos nossas anotações, fotografias, gravações de áudio e vídeos quando houver necessidade, se você assim permitir, como forma de coletar os dados para analisarmos posteriormente. Os sistemas também nos darão informações sobre as ações realizadas neles.

Riscos: As tecnologias a serem utilizadas são comuns e já estão presentes em diversos equipamentos que cercam o seu cotidiano (microcomputadores, telefones celulares, televisores, *tablets*, internet, etc.). Não se pretende com elas interferir em atividades ligadas a sua saúde ou sobrevivência (ex: alimentação e higiene pessoal), terapêuticas, ou de forma irreversível em nenhuma atividade do seu cotidiano. Eventualmente, pode-se adicionar riscos de segurança digital ao se introduzir mais pontos de conexão com a internet em seu ambiente doméstico. Estes não serão maiores do que os já enfrentados normalmente por qualquer usuário de internet em sua casa, com vários dispositivos ligados a um ponto de acesso, e poderão ser desligados a qualquer momento que você quiser. Você pode sentir cansaço ou desconforto durante a participação neste estudo. Serão concedidas todas as oportunidades necessárias para você interromper ou descansar. Você tem pleno direito de solicitar esclarecimentos adicionais, de interromper ou terminar as sessões quando e como quiser. Não há qualquer impedimento para isto nem qualquer necessidade de apresentar uma justificativa ou explicação.

Confidencialidade: Ao longo da realização do estudo, teremos acesso à sua privacidade em seu ambiente doméstico e/ou profissional durante entrevistas, reuniões e na realização dos procedimentos, se você assim permitir. As informações coletadas neste estudo serão tratadas dentro das normas éticas de conduta em pesquisa: 1) serão mantidas em arquivos e servidores seguros dentro do Departamento de Informática da PUC-Rio e serão acessíveis apenas pela equipe de pesquisadores envolvidas no projeto e somente com a finalidade de pesquisa que você consentir; 2) os resultados da pesquisa serão apresentados respeitando-se rigorosamente a sua privacidade e o anonimato de todos participantes, sem a divulgação de nomes, imagens e outros dados que permitam a sua identificação; 3) você poderá solicitar os resultados publicados desta pesquisa se e quando desejar.

TERMO DE CONSENTIMENTO

Você pode solicitar esclarecimentos adicionais ou optar por não colaborar mais com este estudo a qualquer momento, temporária ou definitivamente, quando e como quiser. Não há qualquer impedimento para isto nem qualquer necessidade de apresentar uma justificativa ou explicação.

Para prosseguir, porém, pedimos que manifeste o seu consentimento por escrito marcando as opções abaixo e assinando este termo, do qual você receberá uma cópia para os seus arquivos:

Li e entendi as informações neste termo: ______

As informações neste termo foram explicadas e esclarecidas para mim: ______

Consinto em participar das atividades descritas acima: ______

Autorizo o uso de fotografias, áudio, vídeos e dados de uso dos sistemas coletados sobre mim: ______

Rio de Janeiro,

____ Data: ________________
Participante

____ Data: ________________
Pesquisador

____ Data: ________________
Testemunha